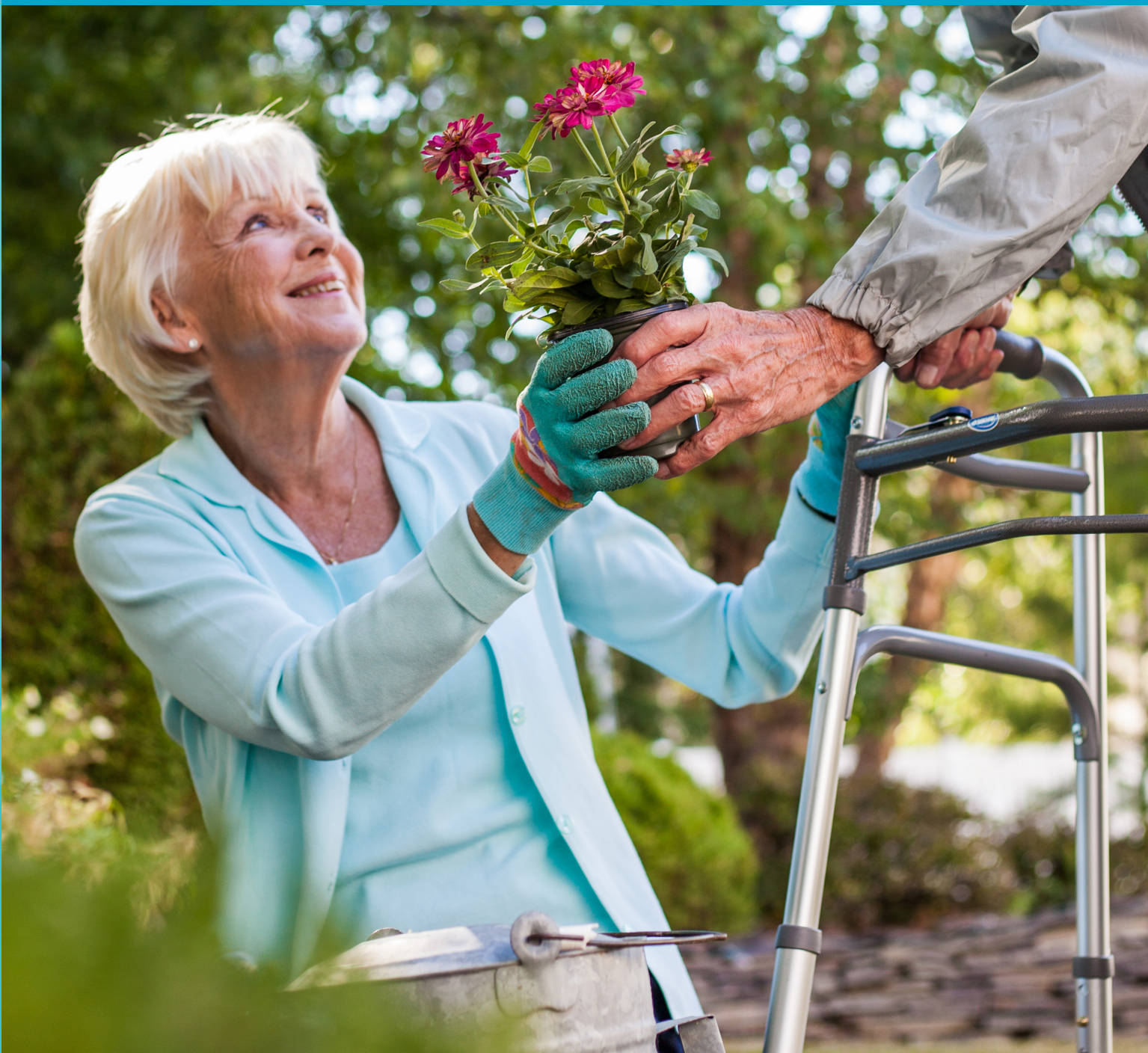




HOSPICE OF THE WESTERN RESERVE

# Caregiver Training Guide

Any question, day or night, call us 800.707.8922.  
Be confident that we're here for you.





# Welcome

**THANK YOU FOR CHOOSING HOSPICE OF THE WESTERN RESERVE** as your caregiving partner. Each of our staff members and volunteers are committed to providing compassionate, exceptional care. We are honored that you and your loved one have placed your trust in us and promise to focus on your priorities, values and goals of care. Your care team includes your loved one (the seriously ill person), you and other family caregivers and your hospice care team members. Our shared goals are directed by the patient and loved ones.

Hospice care is dedicated to personal choice. Your care team members are committed to ensuring that your healthcare choices are respected. They will provide physical assistance and medical care while supporting your emotional and spiritual well-being.

This caregiver training guide offers information that you may need to supplement the services that we provide. It is not meant to be a substitute for our care or services. However, it delivers quick reference to needed, practical information. We have included website links to training videos created specifically for the home caregiver. These may be particularly helpful. Our website [hospicewr.org](http://hospicewr.org) also has numerous other resources that were created to help make home caregiving easier and more enriching.

Most important, we are available 24/7/365 to answer your questions, alleviate your concerns and ease your burdens. Do not hesitate to call anytime, day or night.

It is a privilege to be invited into your life and home and to play a role in your journey.

Sincerely,



**William E. Finn**

*President and CEO,  
Hospice of the Western Reserve*

# Contents

◆ <b>Introduction</b> .....	4
Hospice Care Team Members .....	5
FAQs about Hospice Care .....	5
On-Call Service .....	7
Hospice Care in Assisted Living Communities & Nursing Centers.....	7
Peaceful & Proud Veterans Care.....	8
Services at Hospice Inpatient Care Units.....	8
Extended Care/Continuous Care .....	9
Western Reserve Navigator Palliative Care Services .....	10
Patient Travel Information.....	10
◆ <b>Caring for Your Loved One</b> .....	11
◆ <b>Symptom Management</b> .....	12
Pain .....	12
Shortness of Breath.....	14
Fatigue.....	14
Restlessness.....	15
Helpful Relaxation Techniques .....	15
◆ <b>Understanding Role of Medications</b> .....	16
Medication Disposal Policy .....	17
◆ <b>Oxygen in Comfort Care</b> .....	21
Oxygen Concentrator .....	21
Important Oxygen Safety Reminders.....	22
◆ <b>The Role of Nutrition</b> .....	23
Changes in Taste and Smell.....	23
Thickening Liquids .....	25
Mouth Care.....	25
◆ <b>Catheter and Seizures</b> .....	26
Caring for a Catheter.....	26
Seizures .....	26
◆ <b>Safety and Prevention</b> .....	27
Preventing Infection.....	27
Prevention of Bleeding.....	28
Preventing the Transport of Bed Bugs.....	29
Home Safety.....	29

◆ <b>Providing Physical Assistance to Your Loved One</b> .....	32
Ambulating with Your Loved One .....	32
Assistance Using a Bedpan .....	32
Assistance Out of a Bed to a Chair .....	33
Caring for the Bedbound Patient .....	34
Assistance Using A Commode .....	34
Giving a Bed Bath .....	35
Positioning Your Loved One .....	35
Providing Mouth Care .....	36
Pulling Up a Loved One in Bed .....	36
Changing Bed Sheets .....	37
Assistive Equipment Use .....	37
◆ <b>Cardiopulmonary Care</b> .....	38
Chronic Obstructive Pulmonary Disease (COPD) .....	38
Heart Failure .....	38
Symptoms and Interventions .....	38
◆ <b>Dementia Care</b> .....	40
Caring for Yourself .....	40
Disease Progression .....	40
Dementia Symptoms .....	41
Interventions in Dementia Care .....	43
◆ <b>Caregiver Needs</b> .....	46
Final Days .....	47
Important Things to Attend to When Someone Dies .....	49
◆ <b>Grief and Loss</b> .....	50
◆ <b>Personal Planning</b> .....	52
Advance Care Planning .....	52
The Living Will .....	52
Healthcare Power of Attorney .....	52
Do Not Resuscitate (DNR) Comfort Care Protocol .....	52
(Financial) Power of Attorney .....	52
Organ and Tissue Donation .....	52
Memorial Planning .....	53
Giving Back .....	55
Personal Planning Worksheets .....	56
◆ <b>Reference</b> .....	60



# Introduction

**HOSPICE CARE PROVIDES COMFORT** for the patient and support for you—the caregiver. We work to manage pain and other symptoms of illness. Staff and trained volunteers provide emotional support and can help the whole family explore spiritual questions that often arise when someone is seriously ill. You and your loved one are always in control of the care plan.

## How do you help someone who is dying?

Hospice workers are often asked that question.

The answer can't be found in techniques or textbooks. Medications and treatments are important, but the real work of hospice is **being physically and emotionally present**. Sharing the final stage of life's journey with someone who is dying is the most important thing you can do for them. Simply be there.

This caregiver training guide was created by a number of our staff members working as a team. Allow it to provide you with **an immediate source of information** and to answer many of the questions you might have as you and your loved ones go through this journey.

## Confidence in Your Caregiving

During this stressful time, your care team strives to help you feel more confident in providing care and support to your loved one. We will provide you with medication education, medical information, telephone guidance and ongoing discussions as the disease progresses.

We continually assess both our patient, and you, the caregiver. We want to hear what you feel, see and need throughout this time. Your care team will check in frequently asking, *"How can we help you feel more confident as a caregiver? What can we help you feel more comfortable doing for your loved one?"*

Whatever your questions or concerns, let us know.  
**We are here for you too.**

## Hospice Care Team Members

Specially qualified and trained team members provide hospice services. The individual receiving care and his or her caregivers are vital members of the care team. Together the team creates a plan that maintains individual dignity and ensures all physical, emotional, and spiritual needs are taken care of.

### Your Hospice Care Team Members

A **Primary Care Physician** who is responsible for continued medical management of your loved ones' care. The **Hospice Physician** acts as a resource for hospice medical care, and reviews the plan of care on a regular basis.

A **Hospice Nurse** visits on a regular basis to perform physical assessments, provides education on medications, physical care needs and updates the doctor. Your nurse is valuable source of knowledge.

Your **Social Worker** helps you and your loved ones explore care options, understand legal and financial issues and find emotional support. Social workers are available for individual and family counseling. Our social workers are dedicated to helping the patient and family with the many areas of life impacted by an illness.

**Nursing Assistants** often have the most frequent interactions with patients; they can be a great source of helpful information. Our nursing assistants are experienced in hospice and palliative care. Each of them hold the specialty certification, STNA, meaning they have additional training and have passed a State of Ohio administered exam. They offer important personal care and assistance bathing and dressing. They are also present for emotional support.

**Spiritual Care Coordinators** explore ways to find joy, meaning and purpose in life, even at the end of life. For those who have a religious faith, this may include working closely with your spiritual advisor and faith community. Everyone can benefit from a listening ear, guidance and willingness to explore Universal questions, forgiveness and hope.

**Art and Music Therapists** provide opportunities for life review and the creation of legacies through art and music experiences. They work with patients and caregivers to relieve symptoms and express feelings.

**Pharmacists** strive to relieve pain and manage other symptoms with minimal side effects and maximum benefit.

## Frequently Asked Questions about Hospice Care

### Q: What is hospice care?

**A:** Hospice is compassionate, comfort-oriented care for the seriously ill with an emphasis on pain management, symptom control and spiritual and emotional support for the patient and family. A patient qualifies for hospice care when they have a prognosis of months, rather than years, to live.

### Q: Where can hospice care be provided?

**A:** Anywhere a person calls “home” such as:

- ♦ A private home; group home; nursing or assistant living facility; one of our hospice inpatient units (refer to page 8); a hospital

### Q: How long can a patient receive hospice care?

**A:** Indefinitely, if the patient's condition remains appropriate for hospice care at each certification period. A physician certifies the disease has advanced to the point that the patient has months, rather than years, to live if the illness runs its expected course. After six months, an individual can be recertified. Patients sometimes experience improved health and do not need continuing hospice support. If their condition deteriorates later, they can be re-admitted.

*continued on page 6*

## Hospice Care Team ► CONTINUED FROM PAGE 5

A **Dietitian** provides suggestions on nutrition and symptom management.

**Overnight and Weekend Team Members** assure access to care 24-hours-a-day, 7-days-a-week. Your loved one's comfort and your comfort-level as a caregiver are our priority.

A **Bereavement Coordinator**, trained in supporting those who are grieving, offers supportive services to family members and significant others during the 13 months following a death.

**Volunteer Service Managers** help identify areas in your life where a volunteer may offer assistance. They discuss the role of a volunteer with the patient and caregiver before asking a volunteer to join the team.

**Volunteers** are valuable members of your team and a great source of support. Volunteer staff receive extensive education and are dedicated to maintaining the privacy and dignity of the person receiving care.

Volunteers can help in many ways:

- ◆ Provide a friendly visit or respite for a caregiver
- ◆ Offer spiritual care support
- ◆ Preserve life experiences through audio or video recording
- ◆ Bring a pet to visit
- ◆ Assist with occasional housekeeping and meal preparation
- ◆ Provide simple legal assistance
- ◆ Make periodic phone calls through check-in programs to ensure patient needs are met
- ◆ Provide support to Veterans through our *Peaceful & Proud* Program (*see page 8*)
- ◆ Deliver comfort massage or reiki
- ◆ Provide support and presence in the time surrounding death
- ◆ Help fill a special request to bring fulfillment and comfort through the *Moments to Remember* program (if you have a special request or wish, please tell a team member).

## Frequently Asked Questions about Hospice Care

### Q: Who pays for hospice care?

**A:** Hospice of the Western Reserve is a Medicare/Medicaid certified hospice program, offering a comprehensive Hospice Benefit. This benefit includes hospice care team services, medications and treatments related to the terminal illness, medical supplies and durable medical equipment. Many medical insurance companies have similar plans that cover hospice services.

### Q: Does the patient keep his/her own doctor?

**A:** Yes, hospice patients may continue to be served by their own physicians. Hospice team members work with each physician, serving as a liaison between physician, patient and family. We also have a practice of nine certified hospice physicians on staff. If you wish to change physicians or do not have a primary care physician, and wish for one of our hospice physicians oversee your care, notify your team.

### Q: What if the patient moves during hospice care?

**A:** A transfer to another Medicare-certified hospice can be arranged by your hospice team.

## On-Call Service

Often, questions, concerns, and problems occur during the night or on weekends. We encourage caregivers to use our on-call service when these needs arise. We want you to feel confident calling for support. A nurse is always available on-call.

The on-call number is 440.942.6699 or 800.665.2619. Please refer to the Communication Card on the back of this booklet for names and contact numbers and keep in an easily located area in the home.

If you call for support after 4:30 in the evening, our answering service will promptly answer. The operator will request the patient's name and the reason for your call. Then the operator will ask you to hang up and to not use your telephone while awaiting the call back. The on-call nurse will be notified and he or she will return your call within 15 to 20 minutes. If your call is not returned in 15 to 20 minutes, please call again.

**If there is a change in the patient's condition or a medical emergency, call Hospice of the Western Reserve first. We request that you do not call 911.**

## Hospice Care in Assisted Living Communities & Nursing Centers

Assisted living communities and nursing centers have become more common and more popular. And many younger and healthier people are entering senior communities with the intention of aging in place, even as their medical needs change. The medical community refers to all these living environments as “alternative home” settings. They include: assisted living, nursing facilities, long-term care centers, group homes or other residential care settings.

People living in long-term care settings, including nursing homes, assisted living facilities or group homes, may receive hospice care. We have dedicated Hospice of the Western Reserve teams that partner with alternative home staff to care for the individuals who live in them and require hospice care. We provide the same support and care for a resident as they would for a person living in a private home including additional expertise in pain and symptom management, grief support, on-going consultation and access to our on-call hospice staff. By working together, we enhance the residential facility's excellent services.

### Q: What if the patient no longer wants or needs hospice services?

**A:** We will always honor the wishes of the patient or his/her designated representative for care. If services are no longer needed or desired, the patient must sign a discharge form. There are times when a patient's condition stabilizes, and the hospice care team will discuss discharge. The patient may then join our Western Reserve Navigator program (see page 10) and a team member will call and visit periodically to check on the patient's condition. If you notice changes in the patient's physical health, do not hesitate to call us. Hospice services will always be available when needed.

### Q: How does Hospice of the Western Reserve offer support to caregivers and other loved ones?

**A:** We provide support from clinical staff, personal care for the patient, professional counseling, art and music therapy, spiritual care, pharmacy services and more – all of which help caregivers return to the role of spouse, child, parent or friend. We offer caregiver respite, if family members need a break from the stress of caregiving. Our social workers can help navigate the emotional complexities of serious illness. Our volunteer program is available to create a “*Moment to Remember*” for patients and families by helping them fulfill special wishes and meet day-to-day needs. Our bereavement staff is available to help loved ones manage their grief.

## Hospice Care in Assisted Living Communities & Nursing Centers

► CONTINUED FROM PAGE 7

If the patient is eligible for a hospice benefit through private insurance, then supplies, equipment, and medications needed as a result of the serious illness will be covered.

The charge for room and board is not covered under the Medicare Hospice Benefit. If the patient is living at home, but expects to enter a long-term care facility, the hospice social worker will help locate a facility that works in collaboration with Hospice of the Western Reserve.



### ADDITIONAL SERVICES

## Peaceful & Proud: Personalized Care for Veterans

**To meet the special needs of veterans**, Hospice of the Western Reserve has developed the *Peaceful & Proud* program. Through *Peaceful & Proud*, Hospice of the Western Reserve paid and unpaid staff receive training in post-traumatic stress disorder and other emotional issues for veterans, such as remorse or regret, anxiety and substance abuse.

Veterans are assisted with ethical wills, storytelling, expressive therapies using music and art, Veteran-to-Veteran volunteer pairing, spiritual care and counseling, resources and benefits for veterans and dependents. We recognize veterans for their military service with our Honored Veteran pin.

Hospice can be provided in a patient's home, at our care centers, hospital and assisted living communities or in VA facilities.

## Services at Our Hospice Inpatient Care Units

Hospice of the Western Reserve offers three home-like hospice care units. Each one has an array of services to meet the needs of our patients and loved ones.

For additional information such as: smoking policies, transportation, advanced directives, medications, personal items to bring with you, insurance and billing, room and board charges and physician and nurse practitioner services, please refer to our *Patient and Family Admission Guide*.

### Levels of Care Provided at our Hospice Inpatient Care Units

Your hospice care team, in collaboration with your attending physician, will determine if a change in your loved one's level of care is necessary.

#### *Pain and Symptom Management/ General Inpatient*

The general inpatient (GIP) level of care addresses pain or symptoms that cannot be managed at the patient's current residence. Often, patients return to the same residence once pain and symptoms are controlled or optimally managed. If this is not an option, the hospice team will assist in transitioning to an alternate care setting.

Team members will discuss plans for discharge beginning at the time of admission. Anticipated day of discharge will be communicated once the effectiveness of the plan of care has been determined. General inpatient care is billed to Medicare, Medicaid and commercial insurances. Some commercial insurances charge a co-pay for general inpatient care. **While a patient remains in the GIP level of care, there are no room and board charges.**

If a patient needs to remain at the Hospice Care Unit after the hospice team determines that their symptoms are optimally managed, they must be changed to the Routine Home Care level of care. Short-term stays may be approved in order to facilitate a smooth transition to home or another care setting. Room and board charges apply.

General Inpatient care can also be provided in certain hospitals. The option may be offered based on the patient's attending physician recommendation or the goals of care.

### **Respite Care**

A patient may be admitted for Respite Care if his or her caregiver needs a short interval of rest or relief from caregiving duties. The caregiver must intend to resume caregiving after the respite admission. A Medicare/Medicaid patient may be admitted for up to five days at the Respite level of care with no room and board charges. Some commercial insurance companies also pay for Respite Care. Occasionally, a patient may need to extend Respite Care beyond five days. Arrangements must be made and approved in advance. Room and board fees apply beginning on day six.

### **Residential Care**

We at Hospice of the Western Reserve are committed to providing Residential Care at our Hospice Care Units on a limited basis based on bed availability.

Residential Care assists patients who are unable to care for themselves, have limited capacity or no family caregiving resources or a limited prognosis.

This level of care may also be approved for patients whose symptoms are controlled or optimally managed but who need a few extra days at the inpatient unit to smoothly transition to another care setting. Room and board charges apply to this level of care.

### **Home Away From Home**

When an illness brings a short life expectancy (typically 1 to 14 days), there may be a need to move from the home or hospital to one of our Hospice Care Units. We can help in the transition and provide a peaceful and safe home away from home in the final days. Eligibility criteria apply to this program. Please ask to speak with a hospice team member if you feel this may apply to your situation.

### **Extended Care/Continuous Care**

Continuous care is a level of care that addresses pain, nausea, shortness of breath, or other hard-to-manage symptoms that may require more intense skilled care than can be managed at the patient's current residence without additional skilled nursing intervention. This level of care is meant to be short term. Ongoing reassessment will ensure that the appropriate level of care is maintained to achieve optimum symptom relief. Your Team may, at any point, recommend a transfer to one of our inpatient units if the symptoms persist. This is recommended only if it is no longer feasible to achieve optimum system management in the patients' residence.

Once symptoms are controlled, the patient will return to routine hospice care. Extended Care is not meant to be a substitute for the patient's caregiver in the home or the hospice care team. It is geared toward managing active, difficult symptoms.

### **What can you expect of us while receiving Extended Care?**

In addition to regular visits by your primary team, you may encounter different staff members while you are receiving this service, including trained volunteers.

While in your home, our staff will electronically document the care given during the visit and keep other staff members updated on the patient's response to the plan of care. We will reposition bed bound patients and bathe/change incontinent patients frequently for comfort and to prevent skin breakdown.

## ADDITIONAL SERVICES

## Western Reserve Navigator Palliative Care Services



**Palliative Care** is the medical term for **pain and symptom management**. Western Reserve Navigator may be appropriate for individuals who have been diagnosed with a serious or advanced illness. Unlike hospice care, patients may choose to receive palliative care **while continuing to pursue aggressive treatment and further diagnostic tests**.

Many Navigator patients have more than one serious illness, diabetes as well as heart disease, for example. We focus on helping patients manage their symptoms, supporting them throughout their illness and assisting the family in finding additional resources that improve quality of life.

Minimizing stressful and costly emergency room visits and unnecessary hospitalization is one of Navigator's prime goals. We work collaboratively with your physician to better manage pain and symptoms and to help you avoid the hospital as much as possible.

We can also help families' complete paperwork for programs such as Medicare, Medicaid and Passport. Emotional support is so important during health challenges and our trained volunteers and staff can help with difficult conversations between you and your loved ones about topics such as living wills and Durable Healthcare Power of Attorney.

Our Navigator Team is comprised of Nurse Practitioners, social workers and trained volunteers. You will have toll-free access to a caring nurse 24 hours a day, 7 days a week

## Extended Care/Continuous Care

► CONTINUED FROM PAGE 9

Our staff will remain awake and alert at all times, will conduct themselves as guests in your home, and will be courteous and respectful at all times.

Our staff will bring their own food and beverages and will not smoke while in your home. Staff members are allowed a 30-minute meal break and up to two, 10-minute breaks during an 8–12 hour shift.

### *What can you do to maximize the benefits of Extended Care?*

Stay involved in your loved one's care. Please be available for visits from your primary team and assist in planning for the patient's care when the current symptoms are managed. Ask questions freely and as often as needed.

You are always welcome to make decisions you feel are in the best interest of the patient, such as not turning in bed, refusing medications, etc. Please discuss these decisions with your primary hospice care team.

If at any time you are not satisfied with a particular staff member in your home, please call your primary team or our On-Call service to request a replacement.

## Patient Travel Information

There may be occasions when the person receiving care needs to travel outside of our service area. Many hospices across the United States are willing to collaborate on patient care. Please notify your hospice team as soon as possible, at least five business days prior to traveling, so we may contact a hospice and make arrangements for your access to hospice care.

Our policy supports travel outside of our service area for up to 14 consecutive days. If staying longer, please inform your care team. Your care team will make alternate arrangements and provide appropriate forms to be completed.

If the patient's status changes during travel and requires inpatient care, we will assist with the transfer of hospice care.



# Caring for Your Loved One

**YOUR HOSPICE CARE TEAM** will do their utmost to preserve dignity and comfort. What is dignity? Dignity means many things to many different people. It is about self-respect, life history, family, friends, work, hobbies, feelings, hopes, dreams and life lessons—all the things that are most important to our patients; the things that make your loved one unique and special.

Comfort is easier to define. When making a visit, your care team will focus on the patient, noting pain and other symptoms (such as breathing trouble, nausea, weakness, constipation).

It is important to remember that you, the caregiver, are also part of the circle of care. Please keep your hospice care team informed of your own emotions and feelings. **Your team is here for you.**

Any question, day or night, call us 800.707.8922.  
Be confident that we're here for you.  
[hospicewr.org/caregiver-training](https://hospicewr.org/caregiver-training)

## Pain

Managing pain is most important to us. Pain is whatever the person receiving care says it is, existing whenever he/she says it does.

Please be confident that we will believe you and your loved one if you report pain. We will educate you about pain and pain relief measures. Your team will respond quickly to reports of pain.

### ▶ *Call Your Hospice Care Team if:*

- ◆ There is an increase in pain, new pain or discomfort
- ◆ There is no relief from pain
- ◆ There are side effects, which may include constipation, drowsiness and/or nausea
- ◆ You have questions regarding pain management
- ◆ There is a rapid decline or change in your loved one
- ◆ Questions arise regarding dosage and/or medication changes.

### *Effective Pain Management*

Pain can be physical, emotional or spiritual. Pain can be caused by many factors such as swelling, nerve damage, or progression of a disease. Your team will continually evaluate pain symptoms for your loved one.

Help your loved one try to describe the pain they are feeling. Use words like:

- ◆ Sharp
- ◆ Constant
- ◆ Shooting
- ◆ Squeezing
- ◆ Dull
- ◆ Aching
- ◆ Burning.

**Try to rate the pain. "0" (zero) is no pain. "10" is the worst pain.** (Refer to page 13)

Tell your team what makes the pain better or worse, and how well pain medications are working. We encourage you to write down any and all questions you have. Share them with your care team during visits, or call anytime.

### *Helpful Hints on Describing Pain*

- ◆ Ask the team about what to expect regarding pain and pain management
- ◆ Work with your team to develop a pain management plan
- ◆ Report pain when it first begins
- ◆ Report any problems that you think the pain medications may be causing, as there may be other options
- ◆ Tell your team if you are having any difficulty getting medications or have concerns about them
- ◆ Report feelings of anxiety.

If your loved one can't communicate, look for the following signs of discomfort and speak for your loved one to your care team.

- ◆ Moaning
- ◆ Frowning
- ◆ Restlessness
- ◆ Tenseness
- ◆ Tears.

### *Helpful Hints for Managing Pain*

- ◆ Try various relaxation techniques
- ◆ Distractions can help -- watch a movie, visit with friends, play a game, listen to music
- ◆ Soak in a tub, if possible
- ◆ Hot or cold packs applied to painful areas
- ◆ Try guided imagery
- ◆ Apply light massage or touch.

## WONG Baker FACES® Pain Scale



## 0-10 Numeric Pain Scale



## Notes

[illegible]

## Shortness of Breath

Oxygen therapy is not a treatment for all types of shortness of breath. Some suggestions for managing shortness of breath are below. Consult your hospice care team for other suggestions.

### *What Can Be Done if the Patient is Short of Breath*

- ◆ Try to stay calm
- ◆ Open a window or use fan directed at patient's face to create movement of air
- ◆ Prop head up in bed/chair
- ◆ Apply a cool cloth to face
- ◆ Massage
- ◆ Yoga breath-slow breathing in through nose, out through mouth
- ◆ Conserve patient's energy (sit whenever possible)
- ◆ Take medication as instructed
- ◆ Play soft music or keep room quiet, depending on patient's preference
- ◆ If oxygen has been ordered be sure that it is on.

### ▶) *Call Your Hospice Care Team*

- ◆ Distress is caused by shortness of breath
- ◆ Fever or moist productive cough is present
- ◆ Bluish discoloration of face, nose, fingers, or toes is visible.

## Fatigue

Fatigue is one of the most commonly experienced symptoms in hospice and palliative care patients. Fatigue is a feeling of extreme exhaustion usually resulting from emotional distress, physical distress or an illness. Signs of Fatigue include:

- ◆ Increased sleeping
- ◆ Lack of appetite
- ◆ Not participating in usual activities because of being "just too tired".

### *Helpful Hints:*

- ◆ Plan activities for the "most awake" times of the day
- ◆ Decrease the number of activities planned for one day
- ◆ Change position and location. Avoid staying in bed if able.
- ◆ Routinely incorporate activities to restore energy such as music, meditation, go outdoors.
- ◆ Consider equipment to help with moving such as a walker, cane or wheelchair. Relying on equipment will help to conserve energy for other activities of choice.
- ◆ Allow caregivers to assist with dressing, fixing meals, eating, shopping, cleaning, laundry, etc. to help conserve energy for other activities of choice.
- ◆ Rest as needed. Listen to what the body needs.
- ◆ Attempt to get uninterrupted hours of sleep and avoid interruptions of sleep routines.
- ◆ Increase high protein foods
- ◆ Eat small, more frequent meals.

### ▶) *Call Your Hospice Care Team if:*

- ◆ You notice suggestions above aren't working
- ◆ Patient is unable to have a restful sleep
- ◆ You are unable to administer medications as prescribed
- ◆ The patient appears unsafe (concerns about falling from extreme fatigue)
- ◆ If you would like increased emotional or spiritual support to help with emotional fatigue
- ◆ You or other caregivers are having a hard time coping.

## Restlessness

A person may be described as restless if they are unable to rest, concentrate or focus. As restlessness becomes worse it can turn into agitation and the person is unable to relax given our best efforts. Nearly half of Hospice patients become restless during the last 48 hours of life.

### Signs of Restlessness:

- ◆ Muscle twitching
- ◆ Sleeplessness
- ◆ Pulling on sheets or clothing
- ◆ Trying to get out of bed without a known reason
- ◆ Inability to get comfortable
- ◆ Repositioning or moving without a known reason
- ◆ Fidgeting.

### Helpful Hints:

- ◆ Offer frequent reassurance to the person who is agitated
- ◆ Play soothing music
- ◆ Keep the environment calm (consider decreasing visitors)
- ◆ Calmly read a favorite story, poem or letter
- ◆ Give a gentle massage
- ◆ Distract the person with something familiar such as photos or a task (folding laundry, art, or writing)
- ◆ Keep the person safe if they are wandering and check in frequently
- ◆ Understand that restlessness may be a sign that death is nearing.

### ▶) Call Your Hospice Care Team if:

- ◆ You notice behaviors or signs listed above
- ◆ You are unable to administer medications as prescribed
- ◆ The patient appears unsafe
- ◆ To report what appears to make the restlessness worse (loud noises)
- ◆ To report what appears to make the restlessness better
- ◆ If you wish to consider spiritual support for the patient
- ◆ If the caregiver is having a hard time coping.



## Helpful Relaxation Techniques

**Everyone has his or her own way to relax.** By following these simple steps for relaxation, the ability to manage stress and improve breathing will increase.

- ◆ Find a place free of distraction and interruptions
- ◆ Dim the lights and turn off the television
- ◆ Turn off the phone ringer
- ◆ Turn on soothing music (optional)
- ◆ Lie in bed or sit in a comfortable chair
- ◆ Lie or sit quietly, begin to focus on breathing.

Naturally, breathing will slow down as you begin to focus on exhaling. As breathing slows, let the weight of your body sink into the chair or bed. Imagine a favorite place. Imagine moving around in this place and notice all the colors, sounds and smells of the surroundings.

Enjoy this place and the feeling of relaxation it brings. Movement is free and breathing is easy in this place. Continue to relax and enjoy the music for a time. It is okay to fall asleep. When ready to return from this place, slowly move fingers and toes and slowly return to an upright position.

# Understanding the Role of Medications

Medications come in different forms including: pills, liquids, inhalants, patches, suppositories and ointments. Medications may be changed into different forms depending on the patient's needs, such as difficulty swallowing. **Let your hospice team know if you have less than a two-day supply of any current medication.**

## Medication ☒ DO

- ☒ Read the medication label first.
- ☒ Administer all medicine exactly as it is written on the prescription or as ordered by the physician, for example "with food."
- ☒ Administer routine medication on a regular schedule; timing is very important.
- ☒ Use break-through or in-between medicine as instructed by the hospice nurse and physician to prevent pain from escalating.
- ☒ Tell your hospice team before stopping or changing medications.
- ☒ Keep a written schedule and record when, and how often, medication is taken. (See Appendix)
- ☒ Avoid alcoholic beverages while taking medicine.
- ☒ Tell your hospice nurse about any over-the-counter drugs, vitamins, mineral supplements or herbal remedies that your loved one is currently taking. Supplements can sometimes interfere with medication.

**Keep all medicine out of reach of children and pets.**

## Medication ☒ DO NOT

- ☒ Share medications with anyone else
- ☒ Crush pills unless directed or instructed by your hospice nurse
- ☒ Take more than the amount that is ordered.

## How to Make Medication Time Easier for Patient and Caregiver

- ◆ To make pill swallowing easier, moisten mouth with water or add pills to applesauce or pudding. Some pills may be cut in half.
- ◆ If giving a medication rectally, it is best to administer after a bowel movement if possible. Using a glove, lubricate one finger and insert the medication at least 2/3 of the finger's length.
- ◆ When using liquid medicine, slightly tilt head upright and slowly pour the medicine down the side of the mouth.
- ◆ When administering medication under the tongue or between the cheek and gum, moisten the area with two to five drops of water and then place the pills in that area as directed by your hospice care nurse.

## Medication Schedule and Record

It is helpful to use a medication schedule and record to document all medications given or taken. Inform your care team members where to find the medication schedule so they can make sure your loved one is receiving the correct medication(s) and doses at the right times. Keep the DNR card with the medication schedule. (See Appendix)

## Controlled Substances

Controlled substances are specific medications determined by legal authorities to have a greater need for careful and precise accountability. Examples of controlled substances include many pain medications like morphine and some anxiety medications like Ativan<sup>®</sup> (lorazepam). The use of controlled substances at Hospice of the Western Reserve is based on a patient specific pharmaceutical plan of care, involving critical assessment, careful monitoring, and physician authorization. Any suspected diversion or misuse will be investigated.

## Medication Disposal Policy

The following changes have been implemented by the agency in response to the revisions to the Ohio Revised Code under (B)(9) Section 3712.062 referring to medication disposal and reporting to local law enforcement.

### *To assure the safe and effective disposal of medications:*

**PROCEDURE:** Once a medication is dispensed by the pharmacy, the medication belongs to the patient for whom it was prescribed; therefore no transfer of medications to other people is legally permissible.

Disposal of medications involves rendering them unusable. This is especially critical for controlled substances to prevent diversion.

### *Medications which should be disposed of include the following:*

- ◆ Discontinued medications for patients still actively receiving care when the chance of restarting that medication is remote and/or the chance of medication error is high
- ◆ Expired medications
- ◆ Any questionable medications such as labeling issues, pharmaceutical integrity issues, or other specific factors
- ◆ All medications after a person's death.

## Nursing Home or Facility

The disposal of medications will be handled according to the facility's policies with the review and collaboration with Hospice of the Western Reserve as necessary.

## Home Care

The patient's family/caregiver will be instructed on the disposal of medications on admission and ongoing. A nurse will witness disposal of medications, particularly at the time of death. Documentation of the education, performance of disposal, or the refusal of medications will be entered into the electronic medical record.

If abuse or drug diversion is suspected and the family refuses to dispose of medications or have Hospice of the Western Reserve nurse facilitate disposal, local authorities will be notified.

### *Specific Disposal Methods at Home:*

- ◆ Utilize any community or pharmaceutical program allowing for proper disposal of medications as available
- ◆ Utilize Ohio State Drug Repository Program if able and appropriate
- ◆ Consider eliminating any personal health information from the pharmaceutical labeling (peel label off, crossing off with a permanent black marker).

### *Remove or change original formulation as follows:*

- **Oral dosage forms:** Add liquid to begin dissolution process
- **Suppositories:** Cut up
- **Ointments/Cream:** Eject remainder
- **Transdermal:** Cut up (use gloves if available or use care not to touch transferable medication area)
- **Injectables:** Withdraw remainder
- **Syringes:** Eject remainder
- **Liquid:** Pour out.

## Medication Disposal Policy

► CONTINUED FROM PAGE 17

- ◆ Disposal can occur in the original container (if feasible) or place all medications in a sealable bag, an empty can, or empty plastic container depending on size/volume to be wasted
- ◆ Add a sufficient quantity of water (if no liquid medication is involved already) to allow for dissolution/leaching process to begin
- ◆ Add used coffee grounds, kitty litter, or flour to the bag/can/container to render the mixture undesirable and un-divertible
- ◆ Place in a trash receptacle, preferably inside an opaque bag, if able, to further discourage identification
- ◆ Do NOT attempt to flush medications down a toilet unless specifically instructed to do so.

## Hospice Inpatient Units

Medication destruction will be completed by the nurses (non-controlled substances) and the pharmacist (controlled substances per Ohio Board of Pharmacy authorization and investigational medication as permitted per research protocols). Destruction will be accomplished as above.

Under division (B)(9) of section 3712.062 of the Ohio Revised Code, if the family refuses to dispose of opioids/medications, despite written notice (see caregiver guide addendum), report to the local law enforcement with jurisdiction over the territory in which the patient's home is located the quantity and type of any remaining controlled substances containing opioids that were included in the patient's transdisciplinary plan of care.

Hospice of the Western Reserve will take responsibility at the time of death to facilitate and supervise and/or dispose of controlled substances and other medications.

If abuse or drug diversion is suspected and the family refuses to dispose of medications or have Hospice of the Western Reserve nurse facilitate disposal, local authorities will be notified.

**For additional information from the FDA, please visit [hospicewr.org/fda-safe-disposal](https://www.hospicewr.org/fda-safe-disposal).**

## Notes

---

---

---

---

---

---

---

---

---

---

# Medication Side Effects

Any medicine can have some side effects, but not all people experience them. People react in different ways to medications and combinations of medications. The doctor or hospice nurse can help your loved one work through any side effects to find the best way to manage symptoms.

## Sleepiness

Patients tend to experience fatigue when first starting or increasing a pain medicine. Often after two to three days of following a pain treatment plan, the feeling will pass. The body adjusts to the change. Remember, pain is tiring and with relief of pain, the patient will sleep.

## Constipation

*(having no bowel movement or small, hard stools)*

Certain medication, especially pain medication, will cause constipation. If your loved one is able, drinking more water and fruit juices may help. The hospice nurse routinely starts a laxative when a patient is placed on pain medication. Taking laxatives and/or a stool softener routinely each day will prevent constipation.

### ►) Call your Hospice Care Team

- ♦ If there is no bowel movement in two days.
- ♦ If the patient experiences abdominal pain or cramping, nausea and/or vomiting.
- ♦ If there are black/tarry or coffee ground looking stools as these may indicate the presence of blood.

## Diarrhea

Diarrhea is characterized by loose or watery stools. It may be accompanied by pain and stomach cramping. Diarrhea that does not stop can cause dehydration, weakness, electrolyte imbalances, and increased stomach pain.

### Helpful Hints

- ♦ Try a diet of clear liquids (water, broth, ginger ale), and keep rectal area clean and dry
- ♦ Do not give the patient anti-diarrhea medication unless instructed by the hospice nurse
- ♦ If diarrhea has stopped for 8 to 12 hours, try dry toast, dry crackers, bananas, rice and clear liquids.

### ►) Call your Hospice Care Team

- ♦ If there is lightheadedness, fever, inability to urinate or continued diarrhea.

## Notes

---

---

---

---

---

---

---

---

---

---

## Nausea and Vomiting

Your loved one may experience nausea and vomiting for a number of reasons -- starting a new pain medicine, an infection, anxiety or a change in their illness. Call your hospice nurse if nausea or vomiting begins; there is medicine to help. The patient should not stop taking the pain medicine without speaking to the hospice nurse first.

However, your loved one should avoid dairy products, heavy meals, fatty foods, strong odors, excessive activity and lying down after eating. These may help digestive issues.

### Helpful Hints to Combat Nausea and Vomiting

- ◆ Reduce anxiety with meditation, quiet, music or slow breathing techniques
- ◆ Administer anti-nausea medication as ordered
- ◆ Keep patient still and rested
- ◆ Offer small sips of ginger-ale or peppermint tea
- ◆ Rinse mouth thoroughly after vomiting
- ◆ Take ice chips, popsicles or flavored ice for hydration
- ◆ Continue drinking clear liquids for 24 hours (ginger ale, Jell-O, Gatorade) after vomiting
- ◆ Add bland foods (crackers, dry toast, dry cereal) after 24 hours following liquid diet.

### ❌ DO NOT

- ❌ Eat or drink 1–2 hours after vomiting
- ❌ Be around strong odors
- ❌ Eat any spicy or fatty foods.

### ➤ Call your Hospice Care Team

- ◆ If vomiting returns after starting to drink clear liquids
- ◆ If vomit is bright red or dark brown
- ◆ If constipation continues
- ◆ If the patient is unable to swallow
- ◆ If you are concerned about medicating your loved one.

## Notes

---

---

---

---

---

---

---

---

---

---

## Oxygen in Comfort Care

The use of oxygen is determined by the doctor and hospice nurse and must be used as instructed. The patient or responsible caregiver must sign an Oxygen Agreement Letter when using any oxygen. To notify others that oxygen is in use, you must post “No Smoking” signs that are visible to all visitors. There are two devices provided by your care team that deliver oxygen: oxygen tanks and oxygen concentrators.

### *Oxygen use can be safe if the following rules are followed:*

- ♦ Keep all ignition sources (sparks) away from oxygen. Sources of ignition include: matches, lighters, candles, hair dryers, electric razors, grinders, gas stoves and appliances.
- ♦ The patient should remain at least 10 feet from any source of sparks (radios, TVs, or other electrical equipment.)
- ♦ Keep a fire extinguisher should nearby.
- ♦ Avoid use of oil-based lotions, lip balms, petroleum jelly or aerosol sprays.
- ♦ Do not allow the oxygen user or others in the room to smoke where oxygen is turned on.

### *When Using an Oxygen Tank*

#### ☒ **DO**

- ☒ Keep tank secured in carrying cart in upright position
- ☒ Store tanks not currently being used on the side and away from heat sources
- ☒ Keep valve protection cap in place when tank is not being used
- ☒ Store in a well ventilated area.

#### ☒ **DO NOT**

- ☒ Grab the tank by its valve
- ☒ Drop the tank or allow tanks to hit each other
- ☒ Store tanks in the trunk of a vehicle.

## Oxygen Concentrator

An oxygen concentrator is an electrical device that takes the oxygen from the room air and concentrates it so that you are receiving higher oxygen levels. It provides nearly pure oxygen through a nose tube (cannula) or mask. It may use a humidifier bottle attached to a concentrator to filter the room air. An alarm will sound when the concentrator is initially turned on and if it is not operating properly.

#### ☒ **DO**

- ☒ Plug directly into a wall outlet
- ☒ Store in an open area
- ☒ Always keep sides of the unit a minimum of three inches away from walls, curtains and furniture
- ☒ Make sure oxygen tubing is not kinked or bent
- ☒ Use only distilled water in the humidifier bottle
- ☒ Keep water level in bottle between water-fill lines at all times
- ☒ Empty humidifier bottle when water level reaches bottom line
- ☒ Connect oxygen tubing to humidifier lid
- ☒ Change water in bottle every 24 hours to prevent bacterial growth
- ☒ Check to make sure water is not building up in tubing.

#### ☒ **DO NOT**

- ☒ Plug into outlets that have other appliances plugged into them
- ☒ Use an extension cord
- ☒ Place unit in a closet or enclosed space
- ☒ Add fresh distilled water on top of old water; it will contaminate.

## Important Oxygen Safety Reminders

### ❌ DO NOT SMOKE WHILE OXYGEN IS IN USE.

Smoking refers to both tobacco products and smokeless vapor producing products or devices such as but not limited to, e-cigarettes and hookahs. Smoking devices have heating elements that can serve as an ignition source.

Smoking while using oxygen can cause facial burns, property damage and death. People who smoke pose a threat to themselves, loved ones, caregivers, neighbors and pets.

Many items that would not normally burn in normal air will ignite when increased oxygen levels are present. When oxygen is used, it creates an oxygen-enriched environment. This lowers the temperature at which everyday household items such as bedding, furniture, clothing and even human hair ignite and burn.

### At Our Hospice Inpatient Care Units

All Hospice Inpatient Care Units are located on smoke-free campuses. Because of the use of wall oxygen, visitor smoking is prohibited. Designated smoking locations are for patients only. See *Residence Guides* for smoking policy information.

### Nasal Cannula (nose tube) and Tubing Care

The nasal cannula has two prongs that go gently into the nose. Make sure prongs are curved downwards and bring tubing around each ear to help hold the prongs securely.

Replace nasal cannula or mask if it becomes discolored or cracked. Irritation may occur when using nasal cannula, but can usually be relieved by putting water-based lubricants, such as K-Y Jelly (do not Vaseline; it is flammable) around nasal passages. If tubing causes ear soreness, pad tubing with cotton or gauze around ear area.

### Helpful Hints

- ♦ Clear tubing attached to the oxygen tank/concentrator allows oxygen to travel from equipment to patient through a cannula, or facial mask
- ♦ Tubing is routinely replaced every three months, along with humidifier bottle, cannula and/or mask; it all can be replaced more frequently, if needed
- ♦ Replace tubing if it becomes blocked or kinked.

### ▶️ Call the Oxygen Provider

*phone number is printed on oxygen equipment*

- ♦ When oxygen level meter reads “1”
- ♦ When the equipment is not working properly.

### What to do if Electricity Goes Out

- ♦ Stay calm
- ♦ Since oxygen concentrators use electricity, you have been provided with a minimum of two tanks in case of power outage
- ♦ Take the oxygen tubing that is attached to the concentrator and attach to the oxygen tank, adjust and set oxygen flow rate
- ♦ Call your hospice care team to report any problems or concerns.

## The Role of Nutrition

It is normal for those who are seriously ill to have changes in appetite and in the way they eat and drink. Frequent oral care, small sips of fluid, ointment to the lips and light massage with lotion are all ways to comfort and support the patient at this stage. Try offering food frequently during the day; three to six light meals or smaller portions are usually better tolerated than traditional meal sizes. Offer fluids between meals, instead of with meals to prevent feelings of fullness. Arrange meal times when your loved one is most rested and active. Do not force your loved one to eat.

### Helpful Hints to Improve Nutrition

- ◆ Your loved one should avoid eating when nauseated or in pain
- ◆ Invite others to share meal times—socializing makes everything taste better
- ◆ Set a pretty table—add candles or flowers, play music, garnish food to make it more pleasing to the eye
- ◆ Freshen up hands and face with a warm or cool, moist cloth before eating
- ◆ Have meal options or food choices available
- ◆ Vary food preparation techniques: grill, fry, broil, or roast
- ◆ Have good tasting snacks readily available
- ◆ If nothing tastes good, hydrate with ice chips or Popsicles
- ◆ Use herbs, spices and other seasonings to add flavor.

### Changes in Taste and Smell

Foods will often taste and smell differently as your loved one's illness progresses. This may be due to the illness itself, the medicine or treatments. Even favorite foods may have little or no taste or can taste "off". This can reduce appetite.

To combat a poor appetite, **have your loved one begin each meal or snack with a clean mouth.**

Brush teeth and tongue with a soft toothbrush and use a mouth rinse. Frequently rinse mouth between meals with cool water, mint-flavored water, tea, or ginger ale.

If your loved one complains of foods such as soups, tomato sauces, casseroles, salad dressings, and gravy tasting salty, try adding sugar. If foods taste too sweet, add a pinch of salt and serve cold. If foods taste too bland, use additional herbs and seasonings and experiment with strong flavored foods. Have your loved one try alternate bites of different tasting foods within a meal. For example, a bite of something sweet like pineapple and then a bite of bland cottage cheese. A bite of grilled cheese; then a spoon of tomato soup.

### Helpful Hints

- ◆ If your loved one complains of a metallic or bitter taste, or of dry mouth, give them lemon drops, mints or gum for relief
- ◆ Try serving foods cold or at room temperature, especially meat. This can decrease strong tastes and smells, making them easier to tolerate.
- ◆ Avoid foods usually associated with a bitter taste such as red meat, tomatoes, coffee, tea, and chocolate
- ◆ Add sugar to make food more appealing
- ◆ Season foods with tart flavors such as lemon, lime, other citrus, vinegar, or sweet and sour sauce
- ◆ Don't use metallic containers or metal utensils because it can leave a residual flavor. Plastic, ceramic and glass is neutral.
- ◆ Try frozen grapes, oranges, cantaloupe, watermelon, berries, and bananas for nutrition and hydration.

## The Role of Nutrition

► CONTINUED FROM PAGE 23

### Difficulty Swallowing

When a person has difficulty swallowing, there is increased risk of aspiration (taking food or fluids into the lungs) and choking. To decrease this risk, change the texture of foods and/or thickness of fluids. Foods that are of mixed consistency (liquid along with solid) may be difficult to manage in the mouth and therefore increase the risk of aspiration and choking. Examples of mixed consistency foods are vegetable soup and cold cereal and milk. Also avoid dry, hard, sticky and fibrous foods and any foods with seeds or skins. These types of foods are hard to chew and move around in the mouth, making them more difficult to swallow.

Give your loved one foods that are easy to chew, moist enough to slide down the throat, and evenly textured. Soft food is usually well tolerated but if not, it should be chopped/ground or pureed.

#### ❌ Foods to Avoid

- ❌ Foods that crumble and break into pieces (crackers, chips, pretzels, taco shells)
- ❌ Foods that consist of small pieces (rice, corn, peas, popcorn, granola, raisins, beans, nuts)
- ❌ Food that sticks to the mouth and throat (peanut butter, cream cheese)
- ❌ Food that has fibrous parts or seeds (celery, fruits with peels, tough meat)
- ❌ Food that is hard to chew (tough meat, whole raw vegetables, hard fresh fruit, bagels).

#### ✅ Foods that are generally well tolerated

- ✅ **Starches:** bread, pancakes, waffles, hot cereals, well-cooked pasta, mashed potatoes, muffins, stuffing, lightly toasted bread
- ✅ **Fruits/vegetables:** soft, peeled or pureed fruits and well-cooked vegetables
- ✅ **Dairy:** milk shakes, pudding, custards, ice cream, yogurt, cottage cheese
- ✅ **Protein:** diced, well-cooked meats served with gravies, ground meats and scrambled eggs
- ✅ **Miscellaneous:** soft French fries, cheese pizza, cream soups.

### Helpful Hints for Good Nutrition

- ◆ Serve your loved one's meals in a pleasant and relaxing environment; minimize distractions such as TV
- ◆ Do not leave your loved one alone while eating
- ◆ Allow sufficient time for eating, but avoid long mealtimes so your loved one does not tire
- ◆ If your loved one is bed or chair-bound, position the patient straight up (hips at a 90 degree angle) with the head slightly forward and the chin down to prevent food from going down the airway
- ◆ Serve only one bite at a time and allow time to chew food thoroughly
- ◆ If one side of the mouth is stronger, he or she should chew on that side
- ◆ Make sure your loved one concentrates on swallowing; patients should not breathe or try to talk until food is completely swallowed
- ◆ Coughing can prevent food from going down the airway; the patient should cough as needed
- ◆ Avoid using liquids to clear the mouth of food; that may cause choking
- ◆ If pocketing of food (food collecting in side of mouth) is a problem, apply external pressure to the affected side of the mouth while your loved one is chewing
- ◆ Use pureed baby foods for convenience and add seasonings to enhance flavor
- ◆ Use garnishes to make the pureed food look more attractive
- ◆ After eating, make sure your loved one remains upright for 20 to 30 minutes
- ◆ Use mouth rinse after eating.

## Thickening Liquids

To decrease the chance of choking, liquids can be thickened by adding a commercial food/liquid thickeners to all liquids, including juices, soups, coffee, and milk) to bring them to the correct consistency. Commercial food/liquid thickeners can be found on-line or in many drugstores.

- ◆ Prepare milkshakes in a blender with milk, ice cream or instant breakfast mix
- ◆ Mix and thicken soups in a blender with potatoes and /or potato flakes or baby cereal flakes until smooth
- ◆ Combine pureed fruit and fruit juice to the consistency of syrup
- ◆ Thicken liquids with pureed fruits, yogurt, dried baby cereal, yogurt, or pudding
- ◆ Place a ripe banana into a blender and add to a milkshake, nutritional supplement or juice
- ◆ Add pudding or custard to milk or yogurt.

## Mouth Care

### Tips for providing mouth care:

- ◆ Clean the mouth with toothpaste and soft toothbrush or toothettes
- ◆ Use diluted mouthwash for mouth freshness
- ◆ Use hard candy, ice chips, popsicles, frequent sips of water to treat dry mouth
- ◆ Spray the mouth with a mister filled with cool water to treat dry mouth (a mixture of 1 tsp. of baking soda in 8 oz of water into the mouth can also help treat dry mouth.

## Notes

[illegible]

## Caring for a Catheter

A catheter is a tube inserted into the bladder to help drain urine. It has a small balloon that is blown-up to keep the tube from falling back out. A catheter may be needed due to increased weakness, loss of bladder control, etc. If a catheter becomes needed, the hospice nurse will place it and show the caregiver how to care for it.

### Helpful Hints

- ♦ Wash your hands before and after handling the catheter
- ♦ Check the tubing periodically to see if urine is draining
- ♦ Be sure that the tubing is not kinked or bent
- ♦ Change the drainage bag weekly, as the nurse demonstrated
- ♦ Empty the drainage bag 1–2 times per day; empty leg bags every 3–4 hours
- ♦ Keep the drainage bag below the level of the bladder at all times
- ♦ Do not pull or tug on the catheter or tubing
- ♦ Cleanse the tubing with soap and water daily and when the tubing gets soiled
- ♦ Be sure to begin where the tubing enters the body and work away
- ♦ If the patient is pulling on the catheter, put on a pair of adult briefs to hold it more securely in place, keeping it from moving
- ♦ When turning the patient from side-to-side, move the drainage bag from side-to-side
- ♦ Irrigate the catheter if the nurse has instructed you to do so.

### ▶) Call your Hospice Care Team

- ♦ If the catheter is not draining
- ♦ If the urine has an odor or change in color
- ♦ If the patient spikes a fever.

## Seizures

Seizures look like twitches or tremors in the face and/or extremities. Seizures generally last less than a few minutes. Once a seizure has started, it cannot be stopped.

### ☑ DO

- ☑ Stay calm
- ☑ Protect patient from injury – pad bed rails, remove sharp or hard objects near patient
- ☑ Turn head to the side if mouth secretions are present
- ☑ Allow for rest after seizure has fully ended.

### ☒ DO NOT

- ☒ Force anything between the patient's teeth
- ☒ Put fingers in the mouth
- ☒ Hold down twitching extremities unless it is essential for personal safety.

### ▶) Call your Hospice Care Team

- ♦ If the seizure is a new occurrence, is unusual, lasts longer than a few minutes, or results in injury.

## Preventing Infection

Hand washing is the single most important step in the prevention of any infection. Wash your hands with liquid soap and warm water for a full count of 15–20 seconds. Be sure to wash entire hand to above the wrist, between fingers and under fingernails. Rinse well with warm water. Dry hands with a paper towel.

Alcohol-based hand sanitizers may be used when hands are not visibly soiled. Sanitizers may be kept at the bedside for use when a sink isn't close to the patient care area. Apply a small amount to palm of hand and rub hands together, covering all surfaces of hands and fingers until dry.

### *Wash your hands before and after:*

- ◆ Giving care to the patient
- ◆ Using gloves
- ◆ Using the bathroom
- ◆ Eating or smoking
- ◆ Before preparing meals
- ◆ Having contact with any body fluids
- ◆ Playing with pets, doing yard work and/or housework
- ◆ Returning home from being out
- ◆ Having contact with someone who is ill
- ◆ Coughing or sneezing.

## Influenza (Flu)

This is a highly contagious viral disease that infects the nose, throat and lungs. It is spread from person to person by droplets in the air when the infected person coughs, sneezes or talks. Symptoms develop one to four days after exposure. Symptoms include fever, headache, dry cough, sore throat, extreme fatigue, runny or stuffy nose and muscle aches. The peak flu season is from late December through March.

### *How to Prevent the Flu*

It is important that caregivers and family members get a flu shot in October or November. Some patients have weak immune systems and are unable to respond to the flu vaccine and so they are very susceptible to it. It takes two–three weeks for the body to build antibodies to the vaccine and protect you from the flu. The flu shot lasts approximately 12 months and must be repeated every year.

## Shingles

Shingles is caused by the same virus that causes chicken pox. After recovering from chicken pox, the virus lives on in the body and remains inactive until a patient has a serious illness or trauma that affects the immune system. The virus, when reactivated, causes shingles.

Symptoms of shingles include a tingling feeling on one side of the body which starts itching and then becomes a rash. Fluid filled blisters then develop from the rash. These fluid filled blisters are contagious to caregivers or family members who have not had chicken pox. When these blisters dry and crust over (in about three to five weeks) they are no longer contagious. Visitors and anyone caring for the patient who has not had chicken pox should wait until the patient is no longer contagious before visiting. Check with your doctor immediately.

## Preventing Infection

► CONTINUED FROM PAGE 27

### Blood-borne Pathogens

There are diseases that cause a risk to caregivers such as Hepatitis B and C and AIDS. Hepatitis B and C are viruses that cause serious liver disease and are spread through exposure to blood and other body fluids. AIDS affects the immune system. It is spread through blood and semen. There is no vaccine for AIDS. Use precautions and use latex condoms to prevent the spread through sexual contact.

#### Helpful Hints

- ◆ Use disposable gloves when in contact with the patient's body fluids (blood, urine, stool, wound drainage)
- ◆ Remove gloves and dispose of in trash immediately after use. Place trash soiled with blood or body fluids in a leak-proof plastic bag and place in trash container
- ◆ Clean up body fluid spills as soon as possible
- ◆ Use a 10% bleach and water solution to clean up body fluid spills (1 ounce bleach and 10 ounces water). This solution is good for 24-hours only. A fresh solution needs to be made daily. Use household disinfectants appropriate to surface being cleaned
- ◆ Air out room when possible
- ◆ Place needles, syringes, razors and other sharp objects in a plastic red container – keep sharps and the red container out of the reach of children
- ◆ Do not share personal care items
- ◆ Instruct visitors to wash hands before and after visiting with patient. Request “no visiting” if visitor has a cold or does not feel well
- ◆ If the primary caregiver or other family member is ill, the best choice would be to relieve the caregiver of duties until well again. If this isn't possible, use good handwashing, gloves and a disposable surgical mask to protect the patient.
- ◆ Request advice from your hospice team about vaccines and other precautions.

## Prevention of Bleeding

Patients may be more likely to bleed because of the effects of their illness or medications. Talk with a hospice nurse if any unusual bleeding occurs.

#### Helpful Hints

- ◆ Avoid using sharp objects (*knives/scissors/razors*)
- ◆ Be careful not to bump into your loved one while you are caring for them
- ◆ Use an electric shaver not a manual razor
- ◆ Drink warm fluids and/or eat fruit to help reduce the likelihood of constipation, which can cause bleeding. (See Constipation pg. 19)
- ◆ Use soft toothbrush, sponge, or “toothette” to prevent gums from bleeding; avoid flossing
- ◆ Blow nose gently.

#### ► Call your Hospice Care Team

- ◆ Blood in urine, stool, sputum or vomit
- ◆ Bloody nose (several episodes or one that is not easy to control)
- ◆ Multiple bruises
- ◆ Many small, reddish-purple spots under skin
- ◆ If bleeding occurs, apply moderate pressure to the area if possible and call your care team.

## Preventing the Transport of Bed Bugs

Bed bugs have increasingly become a nuisance throughout the United States. Please report to your hospice team members if bed bugs are suspected or if you know they are present where the patient lives. This will help them to use safety procedures to prevent their transport outside of the home or facility.

When the care team visits a home or facility where bed bugs are suspected or known they are required to wear protective shoe covers and coveralls. In some instances, they may be required to carry a change of clothing in sealed bags to change into prior to leaving. The team will only bring supplies or equipment they need for the visit. These will need to be placed on hard surfaces such as a table, chairs without fabric upholstery or similar pieces of furniture. Any equipment or supplies that the team takes with them from the home or facility will be sealed in a plastic bag before they leave.

When a patient must be moved from a home or facility with known or suspected bed bugs to a hospice in-patient unit, hospital, nursing home, assisted living or other location, the hospice care team will bathe the patient and place them in a clean gown provided by the team.

In this situation, patients and family members are not permitted to bring any personal items such as purses, bags, clothing, luggage, hygiene kits, etc. If medications accompany the patient, they will be placed in a sealed plastic bag. Family members accompanying the patient are asked to inspect their clothing prior to accompanying the patient. The hospice care team will notify the transportation company, funeral home and any other agency or service that will have personnel or equipment coming into the home that there is a possible or confirmed infestation.

## Home Safety

### Electrical

Place electrical cords from medical equipment (bed, oxygen concentrator, etc.) and extension cords out of walkways to prevent tripping or falling. Check extension cords often to make sure they are in good repair. Extension cords should not be overloaded. It is a safer choice to use power strips (surge protectors) or outlet adapters. Keep unused electrical equipment unplugged and place safety covers in unused electrical outlets. Store and use electrical appliances away from water.

### Walkways

Remove as many rugs, runners and mats as possible from areas used by the patient. Secure all loose rugs with double sided tape or rubber matting to prevent falling. Replace or repair torn or frayed rugs. Keep carpets tacked down. Keep stairs and halls clear and well lit, with well-secured rails on both sides. Patients should wear shoes with tread and avoid using the stairs wearing only socks, loose slippers, or smooth-sole shoes.

Outdoor entry ways should be well lit and clear of debris, ice, leaves and snow. Provide secure outside step and porch railings. The house address should be clearly visible from the street during the day and night to guide your hospice care team and other visitors.

### Pet Control

For the safety of your Hospice Care Team and your family pets, we ask that you contain **any** pets prior to team members entering the home. Care Team members have the right to request that pets be contained and to refuse to enter the home if they are not. In the event that a team member is bitten by a family pet, Hospice of the Western Reserve is obligated to report the bite to the health commissioner of the district in which the bite occurred. Please see [codes.ohio.gov/oac/3701-3-28v1](https://codes.ohio.gov/oac/3701-3-28v1) for more information.

## Bathroom

Install grab bars and non-skid mats in showers, tubs and toilet areas to help with transferring the patient. Always check the water temperature for the patient before a bath or shower.

## Telephone

Be certain that all cell and cordless phones and are charged and place hospice care team and emergency phone numbers in easy-to-find places near phones. Keep a phone near the patient's bed or chair, within easy reach. If your loved one is alone for all or part of the day, ask a friend, neighbor or other family member to make periodic calls, or consider an emergency monitoring device.

## Fire Safety

There should be at least one smoke detector for each level of the home. Develop an evacuation plan that includes evacuating those who need help to walk or who are bedbound. Make a secondary escape plan in case the primary plan cannot be carried out. Include family members, neighbors and/or friends to assist in evacuation if necessary. Be certain to communicate your evacuation plans to everyone involved.

Clear all pathways and keep all exits open and unblocked. If you have a deadbolt, keep the key near the door and let everyone in the household know where to find it. Do not leave fireplaces and space heaters unattended while in use. Fireplaces should have screens or doors which are kept closed. Heaters should have screens or an automatic shutoff device. Kerosene heaters require good room ventilation. Never smoke or have open flames in your home if oxygen is being used or stored. Keep fire extinguishers within reach at home and replace before the expiration date.

## Emergency Response

Hospice of the Western Reserve conducts and participates in periodic emergency preparedness drills in order to test the agency's and community's emergency response plans. Team members will communicate with you in the unlikely event that these could affect you.

In the event of an actual emergency, including natural and manmade disasters, life-threatening situations or utility failures, please contact 911. Please notify Hospice of the Western Reserve as soon as feasible. Follow the directions of the community emergency response system from the radio or TV.

Team members will be assigned to contact patients and families in affected emergency areas to assist with emergency response. Please contact Hospice of the Western Reserve to assist in the event that the patient and/or caregiver must be moved or evacuated from their location, or are transported to a hospital or emergency shelter.

## Emergency Medication Distribution

Hospice of the Western Reserve, in cooperation and mutual agreement with health departments throughout Northeast Ohio, is authorized to serve as a closed point of distribution of medications needed to counteract a health threat in the event of a manmade or natural disaster. Medications and health department educational materials would be distributed to patients and their household members by team members and volunteers. This would eliminate the need to access community points of medication distribution.

## Evacuation

Have an evacuation and backup plan ready. Determine where the patient may be moved to, such as the home of a neighbor or friend. Communicate the plan to everyone involved. Prepare to shelter in place if travel or evacuation is prohibited due to weather or other conditions. Notify Hospice of the Western Reserve if the patient and/or caregiver need to change locations.

## Sheltering in Place

There are many online resources that can be used to help plan for emergencies that may affect communities for a few days or possibly longer. County and City Health Departments, Emergency Management Departments and Homeland Security all offer guidance on how to prepare for these situations. Having a seriously ill household member makes these preparations even more important. We encourage you to access these sites and implement plans that meet your particular household situation.

### Some items to consider:

- ◆ Food and water supplies: 3–5 day supply of water (1 gallon per person per day) and unrefrigerated, ready-to-eat foods
- ◆ Medications, patient care supplies and personal care supplies
- ◆ Light sources (flashlight, extra batteries)
- ◆ Battery operated radio or TV
- ◆ First Aid Kit.

## Tornado Safety

Tornado Watch means that local weather conditions exist for a tornado to develop. For Tornado Warnings, remain calm. Move the patient to the lowest level or basement of the home. If there is no basement, go to a windowless interior room or hallway, or move to an inner wall and cover up with blankets. Close all blinds and drapes in the room to aide in reducing flying glass if the window(s) break. If crisis occurs, call 911.

## Utility Failures

In the event of a utility failure, report the problem to the utility company. If the utility failure will require the patient or caregiver to change locations, please notify Hospice of the Western Reserve.

### Power Outage

If the patient uses a medical device or equipment that requires an electrical source, switch to the back-up energy source, if this does not occur automatically. If the patient uses an oxygen concentrator switch to the back-up tanks (see *Oxygen* on page 21). Contact Hospice of the Western Reserve if patient needs to change location or to notify oxygen supplier for additional oxygen as needed. If a crisis occurs, call 911.

### Gas Leak

If you know or suspect a natural gas leak leave the area immediately and go to a safe location. Natural gas has a “rotten egg” smell. Do not do anything that could cause a spark or ignite the gas such as using electrical devices (telephones, light switches, garage door openers, e-cigarettes, etc); using open flames (matches, lighters, cooking, candles, fireplaces) or starting vehicles. Contact the gas company. Inform the local police and fire departments. Do not re-enter the building until the gas company has given the approval. Contact Hospice of the Western Reserve if the patient or caregiver need to change locations.

### Water Outage/Shortage

If a water outage or shortage occurs, use emergency bottled water supply or purchase bottled water. Follow advisories, notices and directions for using or boiling water. Restrict the use of available water for drinking. Contact Hospice of the Western Reserve if the patient or caregiver need to change locations.

## Providing Physical Assistance to Your Loved One

Hospice of the Western Reserve has created 10 short, educational Caregiver Training Videos that demonstrate how to provide essential care during daily activities such as walking, bathing and toileting. These are not meant as a substitute for one-on-one education from your hospice care team but may help you become more confident in your role as caregiver. **For the full series of videos please visit [hospicewr.org/caregiver-training](http://hospicewr.org/caregiver-training).**

If you do not have access to the Internet, or if you prefer in-person training, your Hospice Care Team would be happy to assist you.



### Ambulating with Your Loved One

1. Always stand on the person's weaker side when assisting with ambulation.
2. Place your hands around their waist to guide the person gently and offer support.
3. If the person should fall, guide them slowly to the ground and sit with them. Keep your hands around their waist to guide their center of gravity to the floor landing on their bottom.



### Assistance Using a Bedpan

1. When assisting someone to use a bedpan, it is always recommended to use gloves.
2. First explain to the person what you are planning to do.
3. Lower the bed into a flat position
4. Help the person roll to one side in bed.
5. Place the bedpan squarely under the buttocks
6. Roll the person back over on top of the bedpan
7. Double check to be sure the bedpan is in the right position
8. If able, place the person into a sitting position. Place toilet paper or a warm wash cloth next to the person.
9. Give the person some privacy, but stay close (outside the door) to hear if help is needed.
10. When they are done, lay their head down and carefully roll the person to one side to remove the bedpan
11. Help cleanse the area if assistance is needed and pat dry
12. Dispose of waste in the toilet and clean out the bedpan.
13. Remove gloves and wash hands.



## Assistance Out of a Bed to a Chair

1. Have the person scoot to the side of the bed that they will be sitting on.
2. Raise the head of the bed completely.
3. Allow the person to rest in the position of having their head elevated to avoid light headedness as their body gets used to sitting up.
4. Bring the person to a sitting position on the side of the bed.
5. Allow the person to dangle their legs on the side of the bed. Move slowly and allow time for the blood to circulate to avoid light headedness as someone changes position.
6. Place appropriate footwear on the person's feet to offer stability.
7. Face the person and place your right foot between the person's feet.
8. Bend your knees to ensure you are assisting the person using your legs and not your back.
9. Grab on to the person's pants or use the draw sheet to help pull the patient to a standing position
10. The person should not grab you around your shoulders as this could injure you. The person can hold on to your waist.
11. The person receiving help can push off the side of the bed or hold on to the walker, wheelchair or arms of the chair.
12. Once standing, pivot slowly, hold on to the person's pants or draw sheet, until they feel the surface of the chair behind their knees.
13. Have the person reach both hands backwards to the arms of the chair or continue to hold the waist of the caregiver.
14. Bend your legs to help lower the person as they slowly sit.
15. Gently guide the person by their waist to sit.

## Assistance from Sitting to Standing

1. Assist the person to the edge of the bed or chair
2. Face the person with feet shoulder width apart
3. Reach under the arms, with his/her arms on your shoulders, with your knees bent and back straight
4. Hug your loved one gently while raising to a standing position; allow them to pull on your shoulders for stability
5. Do NOT let go until you are sure the person is stable while standing.



## Caring for the Bedbound Patient

1. When caring for a bedbound patient it is essential to prevent pressure sores or skin tears. Turning or repositioning every two hours is the most effective prevention.
2. A natural tendency is to raise someone's feet up, however, it can be harmful to a person's buttocks if their head is raised above 30 degrees and their feet are elevated at the same time. This position will cause skin breakdown to occur on the buttocks from the skin being pulled in opposite directions.
3. Another prevention strategy to consider when caring for a bedbound person is to keep the skin clean and dry.
4. If there are areas that promote sweating such as on the back, buttocks and under the breasts, clean and pat dry those areas daily. A common "hospice intervention" is to apply antiperspirant under the breasts to help prevent skin breakdown from sweating.



## Assistance Using A Commode

1. When moving with a person, it is essential to explain the purpose, goal and what you are going to do with the person prior to starting the task.
2. Ambulate with a person to the commode until the patient feels the surface of the commode behind their knees.
3. Lower their pants and make sure the lid is open to the commode.
4. Have the person reach both hands backwards to the arms of the commode, or continue to hold the waist of the caregiver.
5. Bend your legs when you help lower the person as they slowly sit. Be sure they are sitting squarely on the commode. Gently guide the person by their waist to sit.
6. Give them toilet paper and a warm wash cloth to clean themselves, if they are able.
7. Allow privacy if needed.
8. After using the commode, offer hand sanitizer and anything else needed to clean up.
9. Help to stand after using the commode by first placing their feet in a comfortable position in front of the commode. On a count of three help to a stand position. Be sure the person gets their bearings prior to taking a step.

LEARN MORE ONLINE

For the full series of videos, please visit [hospicewr.org/caregiver-training](https://hospicewr.org/caregiver-training).



## Giving a Bed Bath

1. Gather the following supplies if giving a bed bath: wash basin, soap, lotion, washcloths and towels, gloves and clean clothes.
2. Place warm water in the basin and add soap to the wet washcloth.
3. Wash, rinse then dry one area at a time using very little soap (to avoid drying of the skin). Cover each cleaned area with a towel or blanket before moving to the next area. A common strategy is to start with the extremities and wash the trunk last.
4. Consider changing the water half way through washing the patient so that it remains warm.
5. Check for dry skin and be sure to use moisturizing soap and lotion if you notice this.
6. Call the nurse if you notice any red areas that do not go away after several hours.
7. Keep sheets dry and wrinkle free to prevent pressure sores.
8. Be sure to turn people and reposition every two hours to prevent pressure sores.

## Skin Care

Keeping the skin moisturized and clean with frequent position changes (every two hours) is important during illness. Specific things to keep in mind about proper skin care:

- ♦ If the skin is very dry use moisturising soaps and lotions
- ♦ After bathing, make sure soap is rinsed off completely and the skin is thoroughly dried
- ♦ Avoid rubbing reddened areas
- ♦ Bathing may not be appropriate everyday for all patients



## Positioning Your Loved One

1. Turning and repositioning of a bedbound person should occur every 2-3 hours to prevent skin breakdown and to maintain general comfort.
2. If using a hospital bed, start by raising the side rail on the side of the patient that they will be turning toward.
3. Raise the bed to the top of your hips to avoid bending over the person – bending over could cause back strain which you want to always avoid.
4. Remove all pillows.
5. If they are able, have the person bend their legs to help them roll to the side.
6. The person should always roll to their weaker side so that the strong arm is pulling their body over.
7. Ask the person to reach and grab the bed rail to their ability while you gently guide the person on to their side.
8. Consider placing a pillow, blanket or towel between the knees and ankles to offer additional comfort and prevent bone resting on bone while lying on their side.
9. Place a pillow behind the back for support and to hold the side-lying position
10. There should not be any weight on the shoulder or knees. Be sure to keep bony prominences are protected.
11. Raise the head of the bed to about 20 degrees for comfort.



## Providing Mouth Care

1. Gather the following supplies for mouth care: soft toothbrush, toothpaste, cup of water, dish to spit into. Additional items such as K-Y jelly to moisturize lips (Vaseline should never be used with oxygen because it is flammable); 1 tsp of baking soda in 8 oz water can help with dry mouth.
2. Have the patient sit up if possible.
3. Check for redness or white patches.
4. Rise mouth and dentures after meals
5. Remove dentures before bed.
6. Notify the hospice team if you notice white patches on the person's gums, tongue or throat. Also notify the hospice team if the person is having difficulty swallowing.



## Pulling Up a Loved One in Bed

*\*This is a two-person task.*

1. If using a hospital bed, start by lowering the side rails.
2. Raise the bed to the top of your hips to avoid bending over the person – bending over could cause back strain which you want to always avoid.
3. Lower the head of the bed so that the person is lying flat.
4. Stand between the hip and shoulder of the person and grab and role the draw sheet with palms facing down. Be sure the draw sheet is between the nipple line and mid-thigh of the person in bed.
5. Have the person bend their knees and dig their heels to help push with their legs to move up in bed. Remind them to do this on your count to three.
6. Remove the pillow from under their head.
7. Further direct the person to hug themselves and lower their chin to avoid skin tears.
8. Both caregivers, turn their front foot forward toward the head of the bed
9. Bend at the knees.
10. On the count of three, pull the person up in bed.
11. Both people lift at the same time, using leg strength and not your backs, to move the person up in bed.
12. Gently replace the person in bed, straighten the sheets and flatten any wrinkles that could be uncomfortable for the person to lay on.

**LEARN MORE ONLINE**

For the full series of videos, please visit [hospicewr.org/caregiver-training](https://hospicewr.org/caregiver-training).

## Changing Bed Sheets

1. If using a hospital bed, start by raising the side rails.
2. Raise the bed to the top of your hips to avoid bending over the person – bending over could cause back strain to your back which you want to always avoid.
3. Lower the head of the bed so that the person is lying flat.
4. Stand between the hip and shoulder of the person. This is where you will grab the draw sheet to move the person on to their side.
5. Ask the person to reach and grab the bed rail – if they are able – while you gently guide the person onto their side.
6. Place the pillow behind the back for support and to hold the side lying position. Position the person's arm out of the way to avoid shoulder discomfort while the person is lying on their side.
7. Begin to change the sheets by rolling the used sheets (including the fitted sheet) under the person along the length of the person's body.
8. Attach the top and bottom corners of the clean fitted sheet and flat sheet. Smooth the clean sheet out under the patient.
9. At this time a **draw sheet** can also be placed under the patient and folded with the clean sheets under the patient. A draw sheet is necessary for someone who is bed bound.
10. To complete making the bed with clean sheets, roll the person to their opposite side, helping them to gently roll over the used sheets and newly placed clean sheets.
11. Once the person is re-positioned on their opposite side with pillows for stability, pull out the used sheets. Place used sheets into the laundry bin.
12. Pull the clean sheets tight and attach the final two corners, making sure any wrinkles are flattened.



### What is a draw sheet?

Learn more at  
[hospicewr.org/Caregiver-Training](https://hospicewr.org/Caregiver-Training)

## Assistive Equipment Use

*Using assistive equipment: walkers, canes, wheelchairs, bath benches and shower seats, etc.*

- ◆ Assistive equipment should not be used alone until the patient has been shown how to use it properly.
- ◆ If the patient is unsteady, a walker or cane should not be used without some assistance during walking.
- ◆ Equipment can be cleaned using soap and water and towel dried before subsequent use.
- ◆ A pad or pillowcase on the wheelchair seat will also help keep it clean.
- ◆ Make sure the chair or bench is secure and dry in the tub/shower before using the equipment.
- ◆ Removing all throw rugs will reduce falls.

### ► Call your Hospice Care Team

- ◆ If the patient has fallen
- ◆ If the equipment is cracked or broken
- ◆ If there are any questions about the proper use of the equipment.

## Cardiopulmonary Care

### Chronic Obstructive Pulmonary Disease (COPD)

COPD is the result of lung problems that have developed over a period of many years. It is often associated with severe asthma, chronic bronchitis, or emphysema. Airflow through the lungs has been hindered by inflammation and/or excess mucus, tightening of muscles around the airways, or by collapse of the airways.

### Heart Failure (HF)

When the heart's pumping ability has become too weak to completely empty its chambers, fluid may back up in the lungs making it very difficult to breathe. Fluid can collect in other body parts as well, causing swelling and discomfort.

### Fatigue

A common symptom of COPD and HF is fatigue. It can be difficult for patients to perform everyday tasks such as walking short distances (i.e. down your driveway or around the house) or sitting up at the dinner table. Your Hospice Team will suggest ways to help conserve energy.

Though rest is helpful, so is exercise. Research shows that the use of large muscle groups in low intensity exercise can increase energy. Patients who are able should take short walks several times a day when it best suits him/ her. If unable to walk, enjoy other physical activities like knitting or painting. Your Hospice team can suggest ideas for physical activities for those who cannot get out of bed.

### Breathing Techniques

There are two breathing techniques that help patients in end-stage cardiopulmonary disease take in more oxygen-rich air. In the first technique, inhale slowly through the nose for two counts, then pucker lips as if blowing out a candle and exhale slowly through the mouth.

In the second technique, sit in a comfortable position with hands resting on the abdomen.

Inhale slowly through the nose, feeling the stomach muscles relax. The chest does not rise. Then, tighten the stomach muscles and exhale slowly through pursed lips.

### Managing Shortness of Breath with Medication

Sometimes it might be suggested by the hospice team that medicine be used to help relieve shortness of breath. Research studies show that the use of an opioid (i.e. morphine) can help reduce exhaustion and relieve a feeling of breathlessness. The hospice team will help explain the use of any medications. At times, the use of a fan may also help lessen the feelings of shortness of breath.

#### ► Call your Hospice Care Team

- ◆ Increased shortness of breath
- ◆ Increased use of an inhaler or nebulizer
- ◆ Excessive fatigue
- ◆ Increased mucus secretions
- ◆ Change in color of secretions
- ◆ Fever
- ◆ Weight gain of two or more pounds in one day
- ◆ Waking during the night unable to breathe
- ◆ Pain in chest, arms, neck, jaw, or back, not relieved by current medications.

### Relaxation

Relaxation may be useful to cope with the physical and mental stress of COPD and HF.

The hospice team can provide assistance in relaxation techniques. Some general examples can be found on page 15.

## Spirituality and Patients with COPD/HF

Exploring spirituality can be helpful emotionally and further enhance relaxation. A Spiritual Care Coordinator from your hospice Team will contact you to offer to visit. Patients are encouraged to meet the Spiritual Care Coordinator. He or she may be helpful in discussing fears, regrets, and hopes.

### Consider the following:

- ◆ What gives you hope?
- ◆ What gives you peace?
- ◆ What provides meaning and purpose in your life?

### Suggestions:

- ◆ Talk about accomplishments or regrets
- ◆ Think about past coping skills
- ◆ Utilize support systems of friends, family, church, or synagogue
- ◆ Engage in complementary / integrative therapies, such as art, music, massage
- ◆ Meditate or use guided imagery
- ◆ Identify sources of inspiration and personal growth/satisfaction
- ◆ Keep a journal
- ◆ Arrange for Pastoral care/supportive presence
- ◆ Pray, read scripture or sacred texts.

## Phone Support: A Call to Connect

Hospice of the Western Reserve's cardiopulmonary phone support team is comprised of volunteers who make weekend phone calls to patients with a cardio or pulmonary diagnosis who reside in a private residence. Caregivers of patients living in nursing facilities, and interested in receiving weekend phone calls from a volunteer, should let the hospice team know. Calls are made once during the weekend and accommodate the patient's schedule. We encourage patients and caregivers to use these calls to discuss any difficulties they may be experiencing.

*A Call to Connect* is a simple yet effective service that keeps the patient and caregiver connected with the hospice team. It provides support and monitoring of symptoms and reminds the family that their hospice care team is available.

## Notes

---

---

---

---

---

---

---

---

---

---

## Caring for Yourself

## Functional

- ## Disease Progression

## Nutritional

- ## Cognitive

- ## Complications

- ## Notes

This image shows a single sheet of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins or other markings on the paper.

# Dementia Symptoms

## Behavior Challenges

Each person with dementia experiences unique changes in behavior. It is important to note that while the changes can be upsetting, the person is not acting this way on purpose. There are underlying reasons such as: pain or illness, noisy environment or over-stimulation, unfamiliar or unrecognizable surroundings. Your loved one may be frustrated because communication is difficult or because they can't complete an activity that used to be simple. Any changes in behavior should be discussed with your hospice team so that a comprehensive pain assessment can be done.

People with dementia sometimes become anxious or agitated. Some may even scream, hit, or push. Try not to take the aggressive behavior personally. Instead, stay calm and use a soft, reassuring tone. Redirect by engaging in a relaxing activity, such as art or music. Contact your Hospice team for more individualized suggestions.

Wandering may not be as much of an issue in late-stage dementia. You may notice the person pacing or walking aimlessly as a result of confusion, restlessness or boredom. For some, it is a way of communicating fears or needs. Make sure the person is getting the right amount of rest, food and drink. Provide reassurance that your loved one is safe. Allow your loved one to wander in areas that are well lit and secure, and take a walk together.

## Creating a Calm Environment

- ◆ Keep the area quiet with few distractions
- ◆ Make note of what “triggers” the behavior and try to avoid it
- ◆ Remove throw rugs and electrical cords that could cause tripping
- ◆ Install childproof latches or doorknobs
- ◆ Post signs for rooms (ex. “Bathroom”, “Kitchen”) to help patient recognize location
- ◆ Keep car keys out of sight
- ◆ Keep identification on him/her at all times (name, contact phone numbers, address)
- ◆ Do not rearrange furniture as this may add to the patient’s confusion.

## Communication

Of all the complications of dementia, the struggle to communicate may be the most troublesome. Memory loss and confusion can create barriers in a once close relationship.

In addition, it is harder to understand the patient’s want and needs. Avoid quizzing your loved one, such as, “Don’t you remember?” Instead, offer reminders. Speak in a loving, patient tone. A firm or loud tone and rapid pace of your words may unintentionally express negative attitudes. A relaxed, lower tone of voice conveys patience. Getting a clear response from the patient is not the goal. Communicating to the patient is what is important—not what you get back.

Non-verbal means of communication become increasingly important as the ability to use and convey words diminishes. Body language, gentle touch and eye contact promote on-going, sensitive communication. Adopting new ways of communication will help maintain the personal relationship and dignity for the person with dementia.

## What Can Be Done

- ◆ Look directly at your loved one, approaching him/her from the front
- ◆ Use a gentle touch to get attention and provide a physical connection
- ◆ Avoid sudden movement as the patient may startle easily
- ◆ Greet your loved one using his/her first name
- ◆ Use short, simple words and sentences, or try gestures to help explain
- ◆ Speak slowly, clearly and deliberately, but do not talk to him/her like a child.

## Dementia Care

- ◆ Give one-step directions
- ◆ Ask questions one at a time. Patiently wait for a response, give extra time to respond
- ◆ Accept silence. He/she may not talk as much as before
- ◆ Eliminate background noise and distractions
- ◆ Maintain eye contact at eye level, for example when he/she is sitting, sit also
- ◆ Smiling helps to gain and keep attention.

## Pain and Discomfort

Pain can go unrecognized and untreated if the person is not able to express degrees of pain or other symptoms. Part of the comprehensive pain assessment is the PAINAD tool. A member of your Hospice Team will use it during each visit to determine his/her level of pain. Simple measures such as repositioning or applying a warm compress can help alleviate discomfort.

Medications may be required to improve the level of comfort.

## Sleeping

Sleep problems are part of normal aging and can be more severe with dementia. Some people with dementia experience “sundowning”, which is characterized by increased agitation, restlessness and confusion at dusk and through the night. This can make it difficult for them to get the sleep needed to function well during the day.

### Suggestions:

- ◆ Limit intake of alcohol and caffeine
- ◆ Plan days with interesting activities and increased exposure to daylight
- ◆ Establish consistently scheduled times for getting up and going to bed
- ◆ Limit daytime napping
- ◆ Establish a bedtime routine
- ◆ Avoid activities that might be upsetting or cause agitation near bedtime
- ◆ Stay calm if your loved one awakens in the middle of the night.

## Eating

Often a person with dementia experiences changes in appetite or ability to eat. While these new eating habits can be distressing for the caregiver, there is a reason, or several reasons, for these changes: loss of interest, inability to chew or swallow, inability to recognize the need to eat, depression, or forgetting how to feed oneself can affect his eating. Talk to your hospice team about well-balanced meals. You may be able replace meals with high calorie snacks.

### Suggestions:

- ◆ Reduce the size of helpings or offer finger foods
- ◆ Alter the flavor of foods since tastes may have changed
- ◆ Chop or puree food to ease chewing and swallowing
- ◆ Avoid exposure to large groups of people during mealtime
- ◆ Offer one food at a time with the correct utensil to avoid confusion.

## Overeating

In some instances, the person cannot sense fullness or differentiate nutritious foods from foods that are less healthy. He/she may not understand the timing of meals, or the differences between breakfast, lunch, dinner and snacks, or is unable to recall when he last ate. In this case, it is better to limit access to snacks, especially sugary ones, which has a negative effect on the individual’s mobility.

### Suggestions:

- ◆ Provide alternatives that satisfy the sweet tooth but are lower in calories, such as sugar-free Jell-O and pudding, cookies containing dried fruit and/or nuts, low sugar candies
- ◆ Introduce stimulating activities throughout the day that help keep focus away from food and eating
- ◆ Maintain a consistent meal schedule
- ◆ Look for snacks the individual may have hidden.

## Swallowing

Difficulties in eating can be the result of physical conditions and an indication that dementia is in late stage. Dysphagia (trouble managing oral secretions or drooling), weakness of a voluntary cough or swallow and involuntary tongue thrusts are common. Changes may also occur in voice quality/ tone (hoarseness/moist sound), frequent throat clearing, poor oral hygiene and weight loss or dehydration.

During mealtimes, the person may experience uncoordinated chewing or swallowing, multiple swallows for each mouthful, pocketing of food in the cheeks, or coughing or sneezing during/ following eating. If the patient experiences pain or discomfort in the throat or chest when swallowing, or has a sensation of food/liquid “sticking” in the throat, something special may have to be done with the head or neck to ease swallowing. In such cases, eating may be so strenuous as to cause fatigue, changes in respiratory patterns, hoarseness or reflux. Talk with your hospice care team if you feel swallowing has become challenging.

### Suggestions:

- ♦ Keep eating and speaking separate to avoid choking
- ♦ Avoid lengthy mealtimes which contribute to fatigue
- ♦ Do not leave your loved one alone while eating
- ♦ Refer to the *Nutrition* section on page 23 for more tips and suggestions.

## Interventions in Dementia Care

### Feeding Tube

Sometimes the placement of a feeding tube is considered. **Studies have shown that artificial nutrition and hydration do not improve the comfort, functional status or quality of life for people with dementia.** This is an individual choice for each family, and your hospice care team will respect your wishes.

Not surprisingly, caregivers are often concerned the person on a feeding tube is experiencing hunger; however, other patients at the end of life who are able to communicate say they experience little or no hunger or thirst. Mouth swabs or ice chips can alleviate what little discomfort they might feel.

### Medications

Upon enrolling with Hospice of the Western Reserve, your hospice nurse and pharmacist reviewed all current medications with the primary physician. Medications are evaluated for effectiveness and appropriateness. New medicines may be ordered depending on the stage of dementia. In general, medications meant to slow the advancement of Alzheimer’s dementia are no longer appropriate during the end stages of the illness when the focus of care is on comfort. All medications will be discussed with the caregiver(s) by the hospice team.

Refer to the *Medication* section on page 16 for more information or ask your hospice team.

### Creative Caregiving

Before beginning any personal care for the person, such as bathing, consider any sensitivity and try to accommodate it. Think about how and when the person with dementia prefers to wash. For instance, is your loved one a late-riser? Does your loved one prefer to wash before bed? Have the room ready, warm and free of drafts. Begin in the least sensitive area of the body, such as hands and arms. Wash hair last or at a separate time. Give him/her something to hold like a sponge ball, and play soothing music or sing familiar songs.

## Connecting with Music

Music is very effective in easing the stresses of dementia. The rhythm, pitch and melody can stimulate different parts of the brain. It can soothe an agitated person, relieve anxiety and decrease pain. It provides a means of reminiscence and can bring a sense of belonging and spirituality. Furthermore, music helps a person with dementia express himself/herself. By singing or playing a familiar song, you may notice changes in facial expression, increased eye contact, vocal activity and movement.

### Suggestions:

- ◆ Sing or hum a familiar song, such as “Take Me Out to the Ball Game”, while completing personal care like bathing or changing the sheets
- ◆ During meal times, play familiar recorded music with a relaxed tempo
- ◆ Rock or move gently to his favorite music, for example, big band or classical music
- ◆ Listen to music from concerts he attended and tell stories about it
- ◆ Play quiet music at bedtime.

**Please Note: Listening to music may conjure both positive and negative memories and feelings.** If certain types of music cause agitation, try another song or stop the music altogether.

## The Importance of Touch

For a person with dementia, touch can be a way of connecting and avoiding a feeling of isolation. A gentle touch provides a feeling of acceptance and a sense of well-being. This improved emotional experience reduces fatigue, anxiety, depression and tension. Use gentle touch when you need to get his/her attention.

### Suggestions:

- ◆ Be clear about your intention, telling him/her exactly what you are going to do
- ◆ Massage over clothing, which may be more comfortable for people with neuropathy
- ◆ Do not require him/her to move positions
- ◆ Avoid areas of skin with irritation or inflammation
- ◆ Keep in mind that skin may be fragile and sensitive.

## Notes

---

---

---

---

---

---

---

---

## Spirituality and People with Dementia

Spirituality is a connection to a higher sense of self and purpose in life. It is expressed in our beliefs, actions, faith and relationships with God or a higher power, self, others and creation. For persons with end-stage dementia, the emotional aspects of spirituality are more meaningful, as they connect with the heart rather than the intellect. Re-affirm that life is precious, love is available and joy in the present moment is possible.

### Suggestions:

- ◆ Stimulate the senses especially through scents, visuals and textures
- ◆ Play videos of scenes of nature with soft calming sounds
- ◆ Read familiar prayers, poems, stories, Scripture passages and blessings
- ◆ View TV programs of religious/spiritual nature
- ◆ Listen to music or sing religious hymns
- ◆ Make religious or cultural rituals or services available
- ◆ Give the patient a spiritual symbol to hold
- ◆ Provide an exercise in guided imagery or meditation
- ◆ Get help from your local religious figure of your faith
- ◆ Celebrate religious/cultural holidays that are a family tradition.

## Unique Grief and Loss for Dementia Caregivers

Feelings of grief and loss can occur at any time when caring for a person with dementia – not just in the final stages. You may feel angry about the disease, saddened that you struggle to communicate, or depressed that your loved one is no longer the person you knew. Focusing on the person now, versus the loss of memory or abilities, may help lessen the grief that you are experiencing.

When the end is near, caregivers deal with what is referred to as anticipatory grief – the reality that death is inevitable. Previously, the end seemed to be far in the future, but changes in the last few months have made the end of the journey closer. There is no right or wrong way to grieve, no calendar and no magic solutions. Feelings of grief are very powerful and often misunderstood. It is physically and emotionally draining, and operates on a timeline all its own. You may experience physical, emotional, intellectual, behavioral and spiritual reactions.

Talking about the grief you are experiencing sometimes requires help from a professional.

Hospice of the Western Reserve offers bereavement services that provide support, encouragement, education and resources during thirteen months following the death of your loved one.

## Notes

---

---

---

---

---

---

---

---

## Caregiver Needs – We Are Here for You

Although you may not consider yourself a caregiver, you are. A caregiver is anyone who cares for a seriously ill person. A caregiver is most often a family member or close friend.

Caring for someone can be both rewarding and stressful. It is not unusual to experience a variety of feelings at this time. These feelings are neither good nor bad. They are your feelings and they may affect your life and wellbeing during the time you are providing care.

Over the years, we have learned from caregivers that caring for someone with a serious illness is a life-changing process. They have taught us that even in the midst of hurt and sadness, there are chances to learn, grow and heal.

Being a caregiver can be a valuable time to create lasting and positive memories together. Unexpectedly, you may find you experience other rewards as a caregiver. You may feel a sense of inner peace or a stronger sense of self-worth. You and your loved one may find moments of joy and laughter in your time together; your relationship may become more emotionally intimate. You may find time to close some unfinished business with your loved one, saying things that you need to say.

### *Caregiving responsibilities can feel overwhelming. Please be aware of:*

- ◆ Excessive fatigue
- ◆ Fear of the unknown
- ◆ A loss of control
- ◆ A loss of “normal” activities
- ◆ Financial worries
- ◆ Social isolation
- ◆ Emotional challenges
- ◆ Feelings of obligation, guilt or resentment
- ◆ Difficulty making plans.

### *In order to effectively care for another person, you need to care for yourself. Here are some valuable suggestions:*

- ◆ Establish visiting hours so that you can have both support and privacy
- ◆ Select a family member or friend to be in charge of relating updates by phone or email to others who are concerned
- ◆ Educate yourself about the condition of the person receiving care. Talk to your physician. Information is empowering
- ◆ Realize that no one can be all things to all people. You may not be able to live up to everyone’s expectations. Try not to dwell on negative comments.

**Maintaining good health is a priority:** Get enough rest, eat properly, and exercise. Identifying your needs as a caregiver is the first step toward taking care of yourself and the person receiving care. Here are some ideas to help you get started. Please talk these over with your Hospice Team.

- ◆ What would you like to have help with?
  - ☐ Household chores
  - ☐ Shopping
  - ☐ Getting through the night
  - ☐ Personal care
  - ☐ What questions do you have about providing care?
- ◆ How do I administer medication?
- ◆ If my loved one is not eating, is starvation a possibility?
- ◆ Can we take outings?
- ◆ What worries you?
- ◆ Being alone and missing my loved one
- ◆ My loved one suffering and being in pain
- ◆ What are my financial obligations?

We are committed to answering your questions, supporting your needs and helping you feel more at peace and confident in caring for your loved one.

## Final Days

Everyone's life is unique, and so is everyone's journey toward death. This is a difficult time because you may not know what to expect during the patient's final days. Your Hospice Care Team will do everything they can to help you feel more confident and less anxious. Your team can provide bedside education on things you can do or say to help your loved one as he or she receives care. We want you to be informed and prepared, but it is natural to feel confused and upset. Be kind and gentle to yourself.

From one-to-three months before death, it is common for a person's world to focus inward. There is a shift away from the outer more social world. This is not a withdrawal of love from you, but a need to focus energy inward. Your presence is very important.

There may be differences in how family members and friends respond. Some may wish to have private time with their loved one. Some may wish to provide personal care. Your hospice team will support you and help you do what feels right for you.

## Signs and Symptoms of Approaching Death

As the patient prepares for the final stage of life, you may notice physical changes taking place. Not all of these signs will appear at the same time and some may never appear at all. Please let us know what you see and experience. Your hospice care team will help you identify these changes and support you through this difficult time. You have undertaken the most precious service by caring for a loved one. It is our desire to be present with you and the patient during the last days and hours. Your hospice team will coordinate this supportive presence for you.

### ► Call your Hospice Care Team

- ◆ **Decreased need for food and drink**, and difficulty swallowing because the body functions are gradually slowing down. There may be difficulty in swallowing. The mouth may become dry and will need to be kept moist. The patient will not experience hunger.
- ◆ **Sleeping/difficult to arouse** is a result of a change in the body's metabolism. Try to spend more time with the patient during those times of greatest awareness.
- ◆ **Restlessness or confusion** is common. The patient may become increasingly confused about time, place and identity of close and familiar people. Reminders as to what day it is, what time it is, and who is in the room will be comforting. Soft music and dim lights may be calming. Keep side rails up for safety.
- ◆ **Visions of people and things** you cannot see are common and not necessarily frightening, but comforting to the patient.
- ◆ **Seizure-like movements** with arms, chest or face in the last few minutes of death are a part of the body's shutdown process. These are not to be considered seizures or seizure activity.
- ◆ **Unusual eye movement** such as side to side.
- ◆ **Incontinence**/decrease in the amount of urine/darker urine color may become a problem. The nurse or hospice nursing assistant can help you obtain pads to place under the patient for more comfort and cleanliness. You may notice a decrease in the amount of urine and it will be darker in color.

- Please let your hospice team know of any special or unique practice/ritual you would like to incorporate at this time. Hospice of the Western Reserve will notify your physician and funeral home at the time of death. Try not be alone during this time. Include family and friends. Ask for assistance with caregiving needs. Use your hospice team for support.

[illegible]

## Important Things to Attend to When Someone Dies

Often when death occurs, even expected death, the sadness can be overwhelming and interfere with the ability to take care of important matters that must be attended to in a timely manner. You may think, “Where do I begin?” and feel at a loss to start the process. Having a checklist may help you be more efficient and thorough. Although this list is not exhaustive, it highlights important tasks that need to be taken care of and when.

### Immediately

Notify necessary parties. Your hospice care team is available to help make these phone calls.

- ◆ Hospice of the Western Reserve – if a hospice team member is not present at death, you should call immediately
- ◆ Family
- ◆ Funeral Home
- ◆ Physician
- ◆ Attorney

Determine whether or not a home needs to be secured if it is now empty. If homeowner is deceased, check with the insurance company regarding any changes in coverage.

### After the Funeral

Obtain the following documents:

- ◆ 10–15 copies of the death certificate
- ◆ Social Security card
- ◆ Marriage Certificate
- ◆ Birth Certificate
- ◆ Insurance policies
- ◆ Deed and titles to property
- ◆ Stocks, bonds and/or IRAs
- ◆ Bank books
- ◆ Honorable discharge papers for Veterans and/or VA claim number
- ◆ Automobile title and registration papers
- ◆ Loan and installment payment books and contracts.

### Contact the following:

- ◆ Government agencies or benefits program, including alliances or unions that may be making payments to the deceased
- ◆ Creditors owed money by the decedent (credit cards, mortgage company, automobile loan agency)
- ◆ Social Security Administration to determine if you are eligible for benefits
- ◆ The deceased’s bank and handle financial matters (roll over joint accounts; determine if deceased had a safe deposit box or a bank security box and follow appropriate procedures)
- ◆ Human Resources at the deceased’s place of employment (if he/she was working) to discover whether there are monies you are entitled to such as vacation pay, death benefits, final wages, retirement plans, or other types of compensation.
- ◆ Your attorney to discuss estate matters. Do not pay any of the deceased’s debts until after meeting with a lawyer.

### Request change of beneficiary or name forms from the following:

- ◆ IRA
- ◆ Life insurance policies
- ◆ Pension plans
- ◆ 401K plans
- ◆ Utilities
- ◆ Stocks/bonds.

Cancel or forward mail and newspaper delivery if necessary. Cancel automatic payments like annual memberships or subscriptions and on-line bill payments.

Make arrangements for final income tax return if appropriate and estate tax return as necessary.

## Grief and Loss

Grief is a normal, necessary, natural reaction to any loss. It is a roller coaster of emotions that involves physical, social, behavior, intellectual and spiritual responses. There is no right or wrong way to grieve. Each person grieves differently, in their own way and on their own timetable. During the course of caring for someone who is seriously ill, you may encounter feelings of grief known as “anticipatory grief.” Even with anticipatory grief, however, there is no way to be fully prepared for the deep sadness you may feel after the death of a loved one.

The Hospice Bereavement Team will continue to offer guidance and support as you adjust to changes in your life. A bereavement coordinator will be assigned to your family and will contact you after the death. A variety of services which include groups and individual support will be explained to you at that time. Additional resources can be found at [hospicewr.org/grief](http://hospicewr.org/grief)

### Suggestions to Promote Healing

- ◆ Be kind to yourself.
- ◆ Schedule a check-up with your family physician, if necessary
- ◆ Be sure to exercise and eat healthy food
- ◆ Check frequently that you have balance in your life: rest, play, meditation and work.
- ◆ Reach out to others.
- ◆ Tell and re-tell the story.
- ◆ Don't fight the tears.
- ◆ Find a creative outlet: music, art, journaling.
- ◆ Confront guilt and regret.
- ◆ Be familiar with normal grief responses.
- ◆ Be patient with yourself. Grief takes time.
- ◆ Have realistic expectations of yourself.

### Children Grieve Too

Like adults, children will grieve in their own unique ways. However, they are often unable to identify, let alone manage these big feelings. Also, the grief may not manifest itself until months or years later. The grief of children can be intermittent and expressed in a variety of ways.

Speak to children in a language they can understand. Be aware of the child's developmental stage and use simple and honest words or phrases. You may need to ask children questions to get a better understanding of how they are feeling. Ask your hospice team for our *children's packet* or to access our bereavement coordinators, who can help with this process.

There is wide variability in the understanding of death at a young age. By age seven, most children understand the key elements of death – that it is permanent and irreversible. Accepted developmental and grief responses of 3–5 year old children include a lack of time/space concepts, belief of death as temporary and reversible, magical thinking, fear of abandonment, and a need for physical comfort, reassurance, and a stable routine. As children mature, so does their understanding of death. The child moves from wanting to understand death in a concrete way to a morbid curiosity about the specifics of death and dying to reacting similarly to adults, but with less coping mechanisms.

As adults, answer all questions simply and honestly, reassure about the future, provide opportunities for feeling expression that include art and music, and allow them to be included in any funeral plans or rituals.

## Common Grief Reactions

**Shock** Shock and numbness is a typical grief reaction. You may feel as if you are on autopilot or just going through the motions. It takes the mind time to grasp that death has occurred.

**Longing** You may feel a deep longing for your beloved. It takes time to accept the reality of the loss and you may find yourself searching for your loved. You might think you hear their voice or sense their presence.

**Sadness** Not only will there be times you feel sad, you may experience waves of sadness. These waves are often unexpected and overwhelming and can bring tears.

**Anger** Anger is one of the intense emotions that is a part of the normal grief reaction. Not everyone feels anger, but many do. You may be angry at the person who died, persons responsible, yourself, the situation or God.

**Guilt and regrets** When someone dies we often second-guess ourselves. You may be wondering what would have happened if you had done or said things differently. You may blame yourself for things you had no control over. Remind yourself you did the best you could at the time.

**Relief** Some bereaved feel a sense of relief after the death. You may be relieved of your constant worries, your responsibilities of caregiving, or your loved one suffering. This is a normal part of the grief process.

**Sleeplessness** Sleeplessness is common shortly after the death. You may have difficulty falling asleep, staying asleep or you may wake very early. Thoughts and deep feelings often surface at night.

**Changes in appetite** You may have an increased or decreased appetite.

## Forgetfulness and inability to concentrate

Many people experience confusion, memory loss and difficulty focusing on tasks at the beginning of their grief journey. It is helpful to write lists, make notes and keep to the familiar.

## Notes

[illegible]

## Personal Planning

### Advance Care Planning

There is no easy way to plan for future health care decisions but the best time to do it is when you are still in good health. During a health crisis, it may be too late, too difficult or just impossible to understand what your loved one wants. You and your loved one can prepare to make the choices that are right for you by developing advance directives in the form of living wills and durable powers of attorney for healthcare. These documents only become active when the person they cover is not able to make or communicate his or her own health care choices. They can be changed at any time.

Please access a free guide to assist with these forms. This all-inclusive booklet, titled *Advance Directives: Making Your Healthcare Choices Known*, includes decision making resources, information and Ohio's living will, healthcare power of attorney and tissue donation forms. Ask a hospice team member for a copy, or visit [hospicewr.org/decisions](http://hospicewr.org/decisions).

### The Living Will

Written instructions tell physicians and family members what life-sustaining treatment is acceptable if an individual becomes unable to make decisions.

A standard Living Will form can be obtained from your hospice care team or online at [hospicewr.org/decisions](http://hospicewr.org/decisions).

### Healthcare Power of Attorney

A document that allows a person to name an advocate to make healthcare decisions on his/her behalf when unable to communicate, either temporarily or permanently.

The person named to make healthcare decisions needs to follow the values and instructions that have been discussed.

### Do Not Resuscitate (DNR) Comfort Care Protocol

A Do Not Resuscitate order is a physician's order; it is prepared by a physician or an advanced practice nurse.

This means that CPR (cardiopulmonary resuscitation) would not be started if the heart or lungs stopped working; there are two types of DNR orders in Ohio.

With a DNR Comfort Care order, a person receives any care that eases pain and suffering, but no resuscitative measure to save or sustain life.

With a DNR Comfort Care Arrest order, a person receives standard medical care until the time that there is a cardiac arrest (heart stops) or a pulmonary arrest (breathing stops) but comfort care will continue.

### (Financial) Power of Attorney

A legal document in which someone gives another person the authority to make specific financial decisions or assumes certain financial responsibilities.

It is advisable to consult an attorney or legal aide to obtain this document. Volunteer attorneys are available for free; please contact your hospice care team if you need a volunteer attorney.

### The Gift of Life: Organ and Tissue Donation

Organ and tissue donations are the gift of life. Through such donations, the lives of others can be prolonged, saved or improved. We realize that this is a difficult decision to make, especially at a time when you are experiencing intense grief, but many families have later said that their pain and loss was somewhat eased by having given a gift of life to another. If you are an organ or tissue donor, please inform your hospice care team so these arrangements can be made for you.

If you would like more information about organ and tissue donation, please ask a team member and arrangements will be made for further discussion.

## Memorial Planning

## The Memorial Service: A Celebration of Life

A memorial service provides a sense of completion for both the deceased and the survivors. Despite the grief and fatigue, spending time with friends and family is a step in the healing process. Sacred texts, poetry, and music are commonly used in planning a memorial service. Reflect on the person's life; think about his or her values, special events, life's work, hobbies, travels, and contributions. It will help you cope with your grief.

In most cases planning a memorial service falls to the immediate survivors. It is also common for the patient to participate in this planning. If the patient has reached an understanding and acceptance about their final moments on earth, planning a memorial service jointly can be very supportive to both of you.

### Things to Remember:

- ◆ **Music** Music affects our feelings and the atmosphere in which we remember our loved one. Select hymns, songs, or other music that are your loved one's favorites, brings comfort or celebrates their life.
- ◆ **Readings** Reflective passages of sacred text, poems, and short stories are all helpful in remembering the person you are celebrating. Some faith traditions may require scripture be read, but many faiths are flexible and will include other types of readings as well.
- ◆ **Symbols of life** Use pictures, items from a person's hobbies, avocations, important moments in life, symbols of accomplishments, or milestones achieved.
- ◆ **Homily, eulogy, meditation** Helps us integrate the music, readings, and symbols with the loved one's life and indicates ways the departed inspired us.

Hospice of the Western Reserve's spiritual care coordinators can assist you in planning a Memorial Service for your loved one and are also available to conduct a memorial service.

## Notes

[illegible]

1. Once a person dies, Probate Court becomes involved to ensure the proper distribution of his/ her assets. We advise you to consult with an attorney regarding this process. An attorney can answer any questions related to probating an estate.
2. While a person is alive, Probate Court may become involved if the patient is determined by a physician to be incompetent (medically unable to make decisions on their own due to confusion, etc.). This determination is then ruled on by the court in a lengthy proceeding. A lawyer needs to instruct the family on this process. (Hospice of the Western Reserve volunteer attorneys cannot provide this service.)

## VA Benefits

There are specific burial benefits that the family may be entitled to if the patient is an honorably-discharged veteran. It is recommended that all questions regarding entitlements be directed to the Department of Veteran Affairs. The patient's discharge papers will be needed.

Cleveland Regional Office  
1240 East 9th Street  
Cleveland, Ohio 44114  
Benefits information and assistance:  
800.827.1000

**Veterans of Foreign Wars:** 216.522.3510 or  
**Veterans Service Commission**  
1849 Prospect Avenue, 2nd Floor  
Cleveland, Ohio 44115  
216.698.2600  
800.750.0750 Ohio Relay Service (TTY)

## Medicaid Recipients

There **may be** financial assistance for burial expenses available through the state. Contact your Medicaid case worker for more information.

## Notes

[illegible]

## Giving Back

Families and friends often ask, “How can we thank you for your services?” By giving back, you help ensure that compassionate care will be available to other families in need. Donations of any size are always welcome. Gifts directly support patient care and family services. And there are many additional, meaningful ways to give back.

What a wonderful, lasting way to carry on the memory of those we love.

### In Lieu of Flowers, Request Donations

Include Hospice of the Western Reserve and [hospicewr.org](http://hospicewr.org) in your loved one’s obituary. You will honor their memory with a lasting gesture that helps others, while saying “thank you” to the caregivers who helped you through a difficult time.

### Create an Estate Plan

What do you wish your philanthropic legacy to be? Perhaps you wish to help other families as you have been helped. Consider the future and make Hospice of the Western Reserve Hospice a beneficiary of your will or life insurance policy or transfer a gift directly from your IRA. Please let us know of your intentions so that we can say “thank you.”

### Inscribe a Memorial Brick or Granite Tribute

Honor your loved one by placing an inscribed stone or brick in any of our three memorial gardens — David Simpson Hospice House, Ames Family Hospice House and the Medina Inpatient Care Center. Other tribute garden options include dedicating a granite bench personalized with a name or sentiment and planting a tribute tree. Visit [hospicewr.org/tributes](http://hospicewr.org/tributes) for options.

### Volunteer

Many of our volunteers have been touched by a hospice experience. You have talents that our patients and families need and we offer a variety of volunteer opportunities for individuals and groups. Pick up groceries. Read a story. Feed a pet. You decide how often and in what way you want to help.

### Share your story

For many, healing is in the telling. Visit our testimonial page at [hospicewr.org/sharemystory](http://hospicewr.org/sharemystory) to share your story with us. You’ll offer more comfort and support to other families than you can imagine.

### Walk with Us

Each June, the annual Walk to Remember attracts more than 3,000 friends of Hospice of the Western Reserve who gather to celebrate life and to remember their loved ones. Details are available at [hospicewr.org/walk](http://hospicewr.org/walk).

### Become a Hospice Hero

Do good while having fun with your friends, service group or civic club, religious organization, or company. Organize a putt-putt golf outing. Hold a bowling event. We’ll provide the help you need to get started and encouragement along the way.

## Personal Information and Records Checklist

LOCATION

☐ **Living Will** \_\_\_\_\_

☐ **Durable Power of Attorney for Healthcare** \_\_\_\_\_

☐ **General Durable Power of Attorney** \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_

☐ **Will**

Attorney \_\_\_\_\_

Executor of will \_\_\_\_\_

*If you do not have a will, we encourage you to prepare one. If you do have a will, it is a good idea to review it at this time and share it with family members and others named in the document. Volunteer Attorneys are available through Hospice of the Western Reserve.*

☐ **Insurance Policies and Policy Numbers**

Life insurance (group and/or individual) \_\_\_\_\_

Health insurance \_\_\_\_\_

Home insurance \_\_\_\_\_

Auto insurance \_\_\_\_\_

Disability insurance \_\_\_\_\_

Renter's insurance \_\_\_\_\_

☐ **Insurance Agent/Broker** Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_

☐ **Real Estate Deeds** Location of property \_\_\_\_\_

Titles in name of \_\_\_\_\_

## Personal Information and Records Checklist

### LOCATION

☐ Mortgages, records, or mortgage payments information

\_\_\_\_\_

☐ Stocks, bonds, certificates of deposit

\_\_\_\_\_

☐ Brokerage firm/broker

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_

☐ Savings account

Name \_\_\_\_\_

Account # \_\_\_\_\_

☐ Checking account

Name \_\_\_\_\_

Account # \_\_\_\_\_

☐ Safe Deposit Box

Location of box and key \_\_\_\_\_

Name box is under \_\_\_\_\_

City, state, federal tax \_\_\_\_\_

☐ Returns for the past several years

\_\_\_\_\_

☐ Birth Certificate

\_\_\_\_\_

☐ Social Security Card

\_\_\_\_\_

☐ Marriage / Divorce certificates

\_\_\_\_\_

☐ Automobile titles

\_\_\_\_\_

*When the person receiving care is no longer able to drive, a transfer of title and change in primary insured is recommended.*

☐ Military discharge papers

\_\_\_\_\_

**Contracts** (e.g. installment purchase agreements)

\_\_\_\_\_

☐ Business records

\_\_\_\_\_

☐ Receipts for furs, jewelry, etc.

\_\_\_\_\_

☐ Credit cards

\_\_\_\_\_

## Memorial Worksheet

Supporting our families in many stages of dealing with a serious illness is a vital part of our mission.

One of the ways we are able to do this is to offer assistance in planning for the time ahead.

Having accurate memorial information available for newspapers and the funeral director is an important task, most of this can be done in advance. Hospice staff members are willing to help you in any way possible. This is best done prior to the death of your loved one, when there is time to think and talk, and gather complete information. The completed form can then be forwarded to the funeral director who is responsible for placing obituary notices and making other arrangements.

We are honored to care for you and your family during this important time. Some families and friends choose to make tribute gifts or to direct gifts in lieu of flowers. Every donation is appreciated and meaningful to our families.

### *Patient Information*

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip Code \_\_\_\_\_

Birthplace \_\_\_\_\_

Came to the area from \_\_\_\_\_ When \_\_\_\_\_

Occupation \_\_\_\_\_

Names of Spouse and Other Loved Ones \_\_\_\_\_

\_\_\_\_\_

Major/Area Employer No. of Yrs. \_\_\_\_\_

Church Religious Affiliation \_\_\_\_\_

Organizations/Offices \_\_\_\_\_

Major Achievements/Honors \_\_\_\_\_

Military Service/Recognition \_\_\_\_\_

Charity of Choice \_\_\_\_\_

## Memorial Planning

For many patients and families, pre-planning the funeral offers an amount of control and comfort. It provides an opportunity for all involved parties to share their ideas and choices at a less stressful time. Most funeral home directors welcome the opportunity to answer questions. Contact the funeral home of your choice to arrange a meeting. The funeral home director can also assist with an “Irrevocable Burial Contract”. This is a preplanned and prepaid funeral. Along with peace-of-mind, preplanned funerals and may also secure a lower price.

Also, the purchase of an “Irrevocable Burial Contract” is considered a legitimate way to spend down liquid assets if qualifying for Medicaid. Speak with the hospice social worker or spiritual care coordinator if you need assistance with funeral planning.

If you have made funeral arrangements or wish to use the services of a specific funeral director, record that information here:

Funeral Home \_\_\_\_\_

Funeral Director \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

Cemetery Name and Plot Number \_\_\_\_\_

Specific instructions \_\_\_\_\_

## Reference

### The Hospice Medicare Benefit and Other Insurance Coverage

Medicare provides a special program for those needing hospice care. The hospice benefit covers services, medications, supplies and equipment needed for the comfort of seriously ill patients. All services, medications, supplies, or equipment related to the seriously ill diagnosis must be pre-authorized by Hospice of the Western Reserve. Medicare pays Hospice of the Western Reserve directly at specified daily rates for care provided. Therefore, Hospice of the Western Reserve delivers care based on the plan of care and is not responsible for care obtained for the patient outside of this plan of care.

Medicare Part D coverage will be assessed upon admission. Payment for medications not authorized under Part D are the patient's responsibility.

These restrictions apply only to the serious illness. Unrelated medical problems may be treated in the usual manner with your insurance coverage.

### Hospice Eligibility Explained

- ◆ Patient has Medicare Part A
- ◆ Patient's doctor and the hospice medical director have confirmed the serious illness
- ◆ Patient signs a statement choosing hospice care benefits
- ◆ Patient receives care from a Medicare-approved hospice (Hospice of the Western Reserve is Medicare-approved)
- ◆ Patient has months rather than years to live.

### The Hospice Benefit Periods Explained

The Medicare Hospice Benefit consists of two 90-day benefit periods followed by an indefinite number of 60-day periods. At the end of each period, the hospice care team must agree that the patient is seriously ill. If the patient is improving or if the illness has stabilized, the hospice care team will discuss alternatives to continuing hospice care with the patient and family.

Medicare allows the patient to discontinue the Medicare Hospice Benefit before a benefit period is over, however, the days left in that period are lost. The next time the patient enters the Medicare Hospice Benefit, they will enter the next period.

If a patient has symptoms such as increased pain, acute nausea, vomiting, or shortness of breath that are proving difficult to manage at home, a few days in a hospital or one of our three hospice inpatient care units may be necessary. The need for this must be assessed by a hospice nurse. If such a trip out of home is needed, the hospice team members will help arrange transportation.

The Medicare Hospice Benefit requires the preauthorization of any hospital stay related to the serious illness, including the emergency room. Call your hospice care team day or night before making a trip to the hospital.

### Medicaid

The Medicaid Hospice Benefit provides the same coverage as Medicare. The patient's Medicaid card will be used to confirm eligibility for this benefit. Because this card is reissued every month, Medicaid asks that we verify hospice eligibility every month as well.

### The Champus Program (TRICARE Insurance)

Because we are a Medicare-certified agency, we can be the provider of hospice services for those persons with Champus coverage, which has the same benefits as the Medicare program.

### Private Insurance

Many, if not most, private insurance carriers have hospice coverage within their program. We will contact the insurance company regarding the coverage. Please contact your primary nurse or social worker with any changes to your healthcare coverage or if you have any questions.

## Financial Responsibilities

I (we) understand that costs which are not approved by Hospice of the Western Reserve and not in compliance with the agreed upon plan of care may include the following:

- ◆ Deductibles and co-payments
- ◆ Care and treatment provided when no insurance coverage is available
- ◆ Care and treatment not related to the serious illness
- ◆ Room and board fees not covered by the third party payer
- ◆ Residential (level of care) room and board charges at a hospice inpatient care unit
- ◆ Any cost incurred for treatment with a physician and/or facility not contracted with Hospice of the Western Reserve
- ◆ Medications not covered under Medicare Part D.

## Billing

Q: Will there be a co-pay or deductible for hospice services?

**A:** Possibly, for some services depending on the insurance coverage and the level of care your loved one receives. Medicare pays Hospice of the Western Reserve directly for each day hospice is responsible for care. During hospice care, the patient should not receive a bill for services covered by Medicare. The current arrangement the patient has under Medicare Part B will continue to cover the doctor's costs. If any questions come up regarding billing, ask your hospice care team for help.

The patient or immediate family will be billed for any amount applied toward his/her personal deductible and/or co-pay after the partial payment has been received from the insurance company. Payment plans and options can be arranged in situations where payment would create a financial hardship for the patient or immediate family members.

A patient or family may also request a financial assessment to determine eligibility for payment plans and other financial options. A team social worker can provide more information and connect you to our financial services team.

## Notes

[illegible]

## Patient Responsibilities

I (we) have consented for hospice services from Hospice of the Western Reserve and agree to:

- ◆ Participate in the development of my Plan of Care in conjunction with the hospice care team, which includes the physician, and continuously discuss goals for my care, activities of daily living and quality of life.
- ◆ Participate in the management of care that may involve personal care, treatments and medication administration.
- ◆ Inform the hospice care team of other agencies providing care and services to me.
- ◆ Be at home and available for the visits scheduled with hospice team members. I understand that I may have to allow one half hour before and after the scheduled time to accommodate traffic, weather conditions and unforeseen events.
- ◆ Notify the hospice care team if I need to cancel or change the time of the scheduled visit.
- ◆ Submit requests for volunteer support no less than 72 hours in advance with the understanding that the team will make every attempt to fulfill my requests.
- ◆ Resolve care issues through the hospice primary nurse. The team leader may be contacted at the designated team office for further assistance with the resolution.
- ◆ Treat hospice caregivers with respect and courtesy, understanding that if they are not afforded such respect and courtesy, they will leave the home immediately. The subsequent visit will be scheduled with the assistance of the team leader.
- ◆ Call the hospice team (if after hours, the on-call team) with any questions, change of condition or symptoms.
- ◆ Call Hospice of the Western Reserve, rather than 911, for immediate assistance.

## Patient and Family Bill of Rights

Learn more at [hospicewr.org/rights](https://hospicewr.org/rights).

### Grievance Procedures

Your satisfaction is our priority. Hospice of the Western Reserve is committed to ideal patient care. We encourage you to speak to us regarding any problem affecting your care. If you are not satisfied with the care provided, we urge you to take the following steps:

- ◆ Talk over your concerns with your primary nurse or social worker. Most concerns will be resolved this way. If your concern is not resolved, call the team leader.
- ◆ If this concern occurs during the weekend or in the evening, request the supervisor on-call when calling the on-call nurse.
- ◆ You may also contact the administrator on-call by calling 216.255.9071.
- ◆ Call or write the Quality Officer at 216.486.6007 who will respond to your concern within 48 hours.
- ◆ If your concern/complaint still has not been addressed to your satisfaction, call the President and Chief Executive Officer at 216.383.3773 or the Chief Clinical Officer at 216.383.3730.
- ◆ At any time, you have the right to refer the problem to:

Ohio Department of Health  
246 N. High Street  
2nd Floor  
Columbus, Ohio 43215-2429

Or, call the toll-free Ohio Department of Health hotline: 800.342.0553

## Corporate Compliance Plan

### Standards of conduct

In concert with our mission, Hospice of the Western Reserve operates in an ethical and conscientious manner; adhering to laws and regulations in providing hospice care and services to the communities we serve. The agency will tolerate no fraud, waste or abuse in conducting our business or in delivering services to our patients and families. As an employee or volunteer of the agency, everyone has the responsibility to act in a manner which upholds the law, to actively participate in and promote compliance, and to report any activity they become aware of that violates any law or regulation.

Anyone can report concerns regarding a lack of compliance in person, by writing, via voicemail, e-mail or by calling the Compliance Hotline voicemail box at 216.383.6688.

Hospice of the Western Reserve's Compliance Hotline voicemail box is in place for use by staff, independent contractors, patients and families seven (7) days a week, 24 hours a day. Individuals can leave a confidential message for the Vice President of Quality if they become aware of an alleged wrong doing or if they have any concerns regarding unethical or illegal conduct at, by or involving the agency. Individuals will be asked to leave their name so they can be contacted for follow-up, if necessary. However, anonymous messages will also be accepted. Only the Compliance Officer (Vice President of Quality) has access to the Compliance Hotline voicemail box.

### Hospice of the Western Reserve Compliance Office

Mary Kay Tyler, MSN, CNP, CHPCA  
Vice President of Quality/Compliance Officer  
Hospice of the Western Reserve, Inc.  
17876 St. Clair Avenue  
Cleveland, Ohio 44110  
Phone: 216.486.6007  
Email: mktyler@hospicewr.org

## Patient Privacy and Confidentiality

The agency implements policies and procedures to accommodate patient privacy rights as required by and specified in the Privacy Rule of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996.

Patients cared for by Hospice of the Western Reserve and its affiliates have the following privacy rights:

- ♦ To have electronic access to the agency's Notice of Privacy Practices via the website [hospicewr.org/privacy](http://hospicewr.org/privacy)
- ♦ To receive a paper copy of the organization's Notice of Privacy Practices upon request
- ♦ To request restrictions on the uses and disclosures of health information
- ♦ To request to receive confidential communication
- ♦ To access their protected health information for inspection and/or copying
- ♦ To amend their healthcare information
- ♦ To request an accounting of disclosures of health information.
- ♦ The privacy policies detail the requirements for each of these rights and provide procedures for implementation. Staff and volunteers at the agency are provided with periodic training regarding patient rights with respect to health information.

How to contact the Privacy Officer  
(Vice President of Quality)

Mary Kay Tyler, MSN, CNP, CHPCA  
Vice President of Quality/Privacy Officer  
Hospice of the Western Reserve, Inc.  
17876 St. Clair Avenue  
Cleveland, Ohio 44110  
Phone: 216.383.3745 or 216.486.6007  
Email: mktyler@hospicewr.org  
HIPAA hotline voicemail: 216.383.6675



# Non-Discrimination Statements

## English

Hospice of the Western Reserve complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex.

Hospice of the Western Reserve does not exclude people or treat them differently because of race, color, national origin, age, disability, or sex.

Hospice of the Western Reserve:

- ◆ Provides free aids and services to people with disabilities to communicate effectively with us, such as:
  - Qualified sign language interpreters
  - Written information in other formats (large print, audio, accessible electronic formats, other formats)
  - Provides free language services to people whose primary language is not English, such as:
    - Qualified interpreters
    - Information written in other languages

If you need these services, contact 216.383.6688.

If you believe that Hospice of the Western Reserve has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, or sex, you can file a grievance with:

Mary Kay Tyler  
 17876 St. Clair Ave  
 Cleveland, Ohio 44110  
 216.383.6688  
 MKTyler@hospicewr.org

You can file a grievance in person or by mail, fax, or email. If you need help filing a grievance, Mary Kay Tyler 216.383.6688 is available to help you. You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights electronically through the Office for Civil Rights Complaint Portal, available at <https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>, or by mail or phone at: U.S. Department of Health and Human Services, 200 Independence Avenue SW., Room 509F, HHH Building, Washington, DC; 20201, 1-800-868-1019, 800-537-7697 (TDD). Complaint forms are available at <http://www.hhs.gov/ocr/office/file/index.html>.

## Espanol (Spanish)

Hospice of the Western Reserve cumple con las leyes federales de derechos civiles aplicables y no discrimina por motivos de raza, color, nacionalidad, edad, discapacidad o sexo. Hospice of the Western Reserve no excluye a las personas ni las trata de forma diferente debido a su origen étnico, color, nacionalidad, edad, discapacidad o sexo.

Hospice of the Western Reserve:

- ♦ Proporciona asistencia y servicios gratuitos a las personas con discapacidades para que se comuniquen de manera eficaz con nosotros, como los siguientes: Intérpretes de lenguaje de señas capacitados.
- ♦ Información escrita en otros formatos (letra grande, audio, formatos electrónicos accesibles, otros formatos).
- ♦ Proporciona servicios lingüísticos gratuitos a personas cuya lengua materna no es el inglés, como los siguientes: Intérpretes capacitados.
- ♦ Información escrita en otros idiomas.

Si necesita recibir estos servicios, comuníquese con 216.383.6688

Si considera que Hospice of the Western Reserve no le proporcionó estos servicios o lo discriminó de otra manera por motivos de origen étnico, color, nacionalidad, edad, discapacidad o sexo, puede presentar un reclamo a la siguiente persona:

Mary Kay Tyler  
17876 St Clair Ave  
Cleveland, OH 44110  
216.383.6688  
MKTyler@hospicewr.org

Puede presentar el reclamo en persona o por correo postal, fax o correo electrónico. Si necesita ayuda para hacerlo, Mary Kay Tyler 216.383.6688 está a su disposición para brindársela. También puede presentar un reclamo de derechos civiles ante la Office for Civil Rights (Oficina de Derechos Civiles) del Department of Health and Human Services (Departamento de Salud y Servicios Humanos) de EE. UU. de manera electrónica a través de Office for Civil Rights Complaint Portal, disponible en <https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>, o bien, por correo postal a la siguiente dirección o por teléfono a los números que figuran a continuación: U.S. Department of Health and Human Services 200 Independence Avenue, SW Room 509F, HHH Building Washington, D.C. 20201 800.368.1019, 800.537.7697 (TDD) Puede obtener los formularios de reclamo en el sitio web <http://www.hhs.gov/ocr/office/file/index.html>.

If you do not speak English language assistance services, free of charge, are available to you. Call 216.383.6688.

Hospice of the Western Reserve complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex.

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 216.383.6688.

Hospice of the Western Reserve cumple con las leyes federales de derechos civiles aplicables y no discrimina por motivos de raza, color, nacionalidad, edad, discapacidad o sexo.

注意: 如果您使用繁體中文, 您可以免費獲得語言援助服務。請致電 216.383.6688.

Hospice of the Western Reserve 遵守適用的聯邦民權法律規定, 不因種族、膚色、民族血統、年齡、殘障或性別而歧視任何人。

ہیوخلل عدعاسملا تامدخ ناف ءءخلل ركذا ثدحتت تنك اذا :عظوحلم - (مقر  
مقرب لصتا . ن اءملاب كل رفاووت

:مءابل و مصلا فءاھ -216.383.6688.

قرعلا ساسأ ىلع زىمى الو اھب لومعمل ءىل اردفلا ءىندمل قووقل حل نىناوقب  
وأنسل وأن طولاً لصالاً مزلتلى Hospice of the Western Reserve وأنولاً وأن  
سنجلأ وأن ءقاعلأ

AANDACHT: Als u nederlands spreekt, kunt u gratis gebruikmaken van de taalkundige diensten. Bel 216.383.6688.

Hospice of the Western Reserve voldoet aan de geldende wettelijke bepalingen over burgerrechten en discrimineert niet op basis van ras, huidskleur, afkomst, leeftijd, handicap of geslacht.

ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 216.383.6688.

Hospice of the Western Reserve respecte les lois fédérales en vigueur relatives aux droits civiques et ne pratique aucune discrimination basée sur la race, la couleur de peau, l'origine nationale, l'âge, le sexe ou un handicap.

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 216.383.6688.

Hospice of the Western Reserve erfüllt geltenden bundesstaatliche Menschenrechtsgesetze und lehnt jegliche Diskriminierung aufgrund von Rasse, Hautfarbe, Herkunft, Alter, Behinderung oder Geschlecht ab.

ATTENZIONE: In caso la lingua parlata sia l'italiano, sono disponibili servizi di assistenza linguistica gratuiti. Chiamare il numero 216.383.6688.

Hospice of the Western Reserve è conforme a tutte le leggi federali vigenti in materia di diritti civili e non pone in essere discriminazioni sulla base di razza, colore, origine nazionale, età, disabilità o sesso.

注意事項: 日本語を話される場合、無料の言語支援をご利用いただけます。216.383.6688まで、お電話にてご連絡ください。

Hospice of the Western Reserve は適用される連邦公民権法を遵守し、人種、肌の色、出身国、年齢、障害または性別に基づく差別をいたしません。

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 216.383.6688 번으로 전화해 주십시오.

Hospice of the Western Reserve 은(는) 관련 연방 공민권법을 준수하며 인종, 피부색, 출신 국가, 연령, 장애 또는 성별을 이유로 차별하지 않습니다.

UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer 216.383.6688.

Hospice of the Western Reserve postępuje zgodnie z obowiązującymi federalnymi prawami obywatelskimi i nie dopuszcza się dyskryminacji ze względu na rasę, kolor skóry, pochodzenie, wiek, niepełnosprawność bądź płeć.

ATENÇÃO: Se fala português, encontram-se disponíveis serviços linguísticos, grátis. Ligue para 216.383.6688.

Hospice of the Western Reserve cumpre as leis de direitos civis federais aplicáveis e não exerce discriminação com base na raça, cor, nacionalidade, idade, deficiência ou sexo.

ATENȚIE: Dacă vorbiți limba română, vă stau la dispoziție servicii de asistență lingvistică, gratuit. Sunați la 216.383.6688.

Hospice of the Western Reserve se conformează legilor Federale privind drepturile civile și nu discriminează pe baza rasei, culorii, originii naționale, vârstei, dizabilităților sau sexului.

ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 216.383.6688.

Hospice of the Western Reserve соблюдает применимое федеральное законодательство в области гражданских прав и не допускает дискриминации по признакам расы, цвета кожи, национальной принадлежности, возраста, инвалидности или пола.

OBAVJEŠTENJE: Ako govorite srpsko-hrvatski, usluge jezičke pomoći dostupne su vam besplatno. Nazovite 216.383.6688.

Hospice of the Western Reserve pridržava se važećih saveznih zakona o građanskim pravima i ne pravi diskriminaciju po osnovu rase, boje kože, nacionalnog porijekla, godina starosti, invaliditeta ili pola.

DİKKAT: Eğer Türkçe konuşuyor iseniz, dil yardımı hizmetlerinden ücretsiz olarak yararlanabilirsiniz. 216.383.6688 irtibat numaralarını arayın.

Hospice of the Western Reserve yürürlükteki Federal medeni haklar yasalarına uygun hareket eder ve ırk, renk, ulusal köken, yaş, engellilik durumu ve cinsiyet ayrımcılığı yapmaz.

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 216.383.6688.

Hospice of the Western Reserve tuân thủ luật dân quyền hiện hành của Liên bang và không phân biệt đối xử dựa trên chủng tộc, màu da, nguồn gốc quốc gia, độ tuổi, khuyết tật, hoặc giới tính.

AKIYESI: Bi o ba nso èdè Yorùbú qfè ni iranlọwọ lori èdè wa fun yin o. È pe ẹrọ-ibanisọrọ yi 216.383.6688.

Hospice of the Western Reserve ẹẹle ilana ofin ijọba apapọ lori etọ arailu ati pe wọn ko gbọdọ sojuṣaaju lori ọrọ ẹya, àwọ, ilu-abinibi, ọjọ-ori, abarapa tabi jije ọkunrin tabi obinrin.

## Notes

[illegible]



PATIENT NAME \_\_\_\_\_

---

PHYSICIAN NAME \_\_\_\_\_

NURSE NAME \_\_\_\_\_

PHARMACY NAME – RELATED \_\_\_\_\_

---

UNRELATED

[illegible]



## OUR MISSION

Hospice of the Western Reserve  
provides palliative and end-of-life care,  
caregiver support, and bereavement services  
throughout Northern Ohio.

In celebration of the individual worth of each life,  
we strive to relieve suffering, enhance comfort,  
promote quality of life, foster choice in  
end-of-life care, and support  
effective grieving.